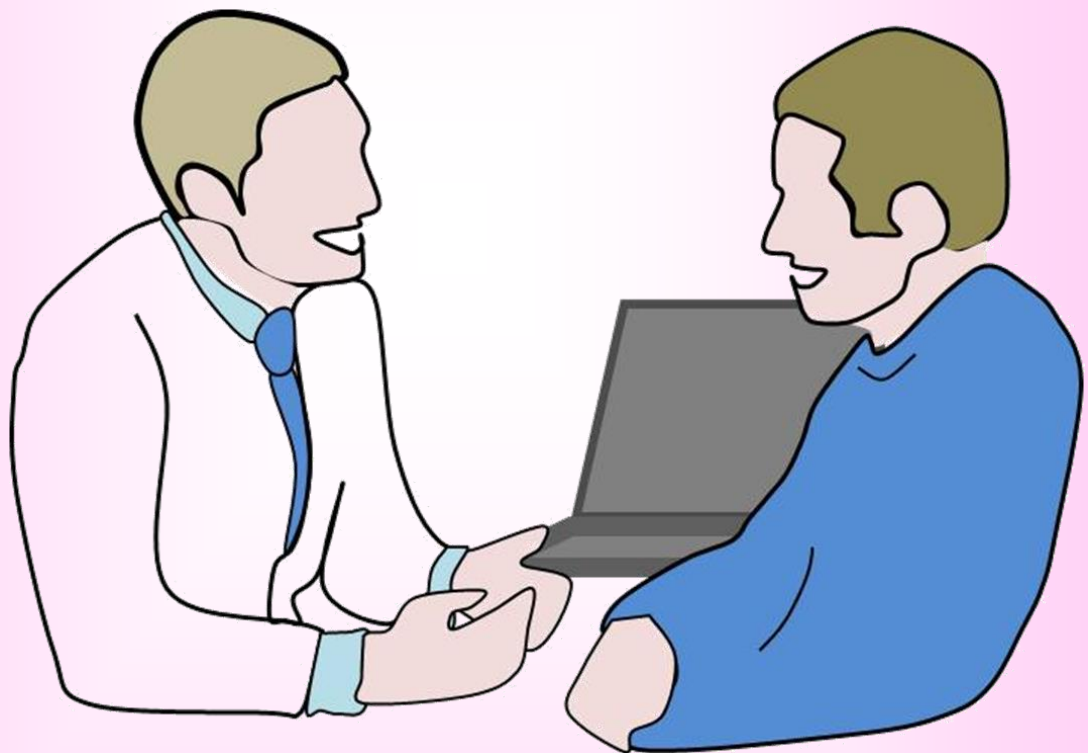


# **The Views of Carers of Adults with Intellectual Disabilities on Annual Health Checks**

## **Final Report**



Margaret Tyson

Simon McElduff

Jillian Pawlyn

Patrick McElduff

Susan Kellett

**The Authors:****Margaret Tyson**

BSc; MPHe; PhD

Honorary Researcher, Institute of Cancer Services, University of Manchester

**Simon McElduff**

University of Newcastle, Australia.

**Jillian Pawlyn**

MSc, PCTHE (OBU); RNLD SCLD TCH (UK).

Senior Lecturer and Subject Lead - Learning Disabilities at De Montfort University, Leicester.

**Patrick McElduff****Associate Professor of Biostatistics**

University of Newcastle, Australia.

**Susan Kellett**

Learning Disability Carers Community

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## Summary

### Background

The Annual Health Check (AHC) for people with Intellectual Disabilities (ID) was set up in 2008-2009 to monitor their health under the NHS Direct Enhanced Services (DES). Around 85% of GPs are signed up to the scheme but currently only about 44% of ID people receive an AHC.

The aim of this study was to discover the percentage of adults with ID reported as not having AHC by carers, the reasons for not having AHC and their satisfaction with the AHC. Also, it was determined from comments how the Annual Health Check can be improved.

Various comparisons were made for example, the demographic/biographic data of carer was compared with whether or not the person with ID goes for AHCs. Gender and the level of intellectual disability of the ID person was compared with whether or not the person with ID goes for AHCs. Also, whether a doctor or nurse doing AHC affects the person's or carer's satisfaction. Satisfaction with the AHC before and after being told the tests available and a comparison of the number of tests being done against doctor or nurse and against satisfaction levels were also determined. Qualitative comparisons/correlations included themed comparisons of comments.

### Methods

A year-long e-survey was compiled to collect both quantitative and qualitative data from April 2014 and distributed online. A few surveys were completed by hand. Both carers of people with ID who attended and did not attend AHCs were asked to complete the survey to discover reasons for non-attendance. The organisations "Learning Disability Carers Community" and "Karen's Page" distributed the e-survey through their websites, Facebook pages and Twitter accounts and the link was reinforced by adding text to encourage participation. The survey was included in the NHS electronic bulletin to CCGs in August 2014 together with a link to a printable edition for carers not able to access the e-survey. The survey was also distributed to various organisations such as county councils and charity organizations many of whom mentioned it on their websites with a link. Survey participants were informed that they could withdraw from the study at any time up until data analysis commenced. Once unusable data were eliminated there were 280 respondent data. A conference presentation was given to present preliminary data and to encourage delegates to distribute the survey.

Quantitatively, continuous outcomes were summarised with the variables mean, median, standard deviations and range. Categorical outcomes were summarized using counts and percentages. A primary outcome was the satisfaction with AHC which was rated very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied and very satisfied. To determine the variables associated with AHC, linear regression was used and standard errors and therefore p-values were calculated based on the robust variance estimator because the data are not normally distributed.

For the predictors of whether the person with intellectual disability attended an AHC or not t-tests were used if the demographics were continuous and chi-square tests were used if they were categorical.

Survey participants were informed that they could withdraw from the study at any time up until data analysis commenced. Qualitatively survey data were anonymised using a unique personal ID code (within the report respondents identified as R number) any names of places or people mentioned in the transcript were removed to ensure that identity was protected.

Themes were identified and emergent themes presented. Data analysis was conducted using thematic analysis. Patterns Indicated overarching themes and general statements.

## Results

Twice as many males as females were found to be ID and percentage levels of ID were 13.1% mild, 30% moderate, 41.3% severe and 15.5% profound. These percentages did not agree with other studies due to differences in criteria and bias.

45.5% of the surveyed carers (or ID people) said the people with ID they cared for did not have an AHC which, in line with other studies, was lower than the AHCs available (offered by 85% of GPs). This figure was contributed to by 52.7% of carers not receiving a GP appointment letter and 62% not receiving an appointment reminder.

People with ID were more likely to have an AHC if cared for by a paid carer rather than by the family. Although 83% of those surveyed were cared for by family.

Several reasons were given by GPs to carers for not offering AHCs including lack of funds.

Carers gave reasons for non-attendance of the AHC even when offered, including challenging behaviour by the person with ID, carer's health, lack of support, travelling distance and the health of the person with ID being good enough not to need an AHC. Attendance was also affected by confusion over AHCs and Health Action Plans (HAPs) and also confusion about and cancelled appointments. Some carers felt that AHCs should be done in places other than GPs. There was also a suggestion that the carers (parents, etc.) should be given the right to attend with the person they care for.

The content of the AHC was found to be very variable; straightforward tests such as those for weight, height and BP and which indicated a wide range of illnesses were most common. For similar reasons, questions such as whether the person smokes or drinks alcohol were the most asked. Importantly, examinations of testicles and breasts were rarely done despite the serious diseases that may be discovered.

Carer satisfaction with the AHC was unaffected by whether a doctor or nurse did it but the level of satisfaction reduced with fewer tests being done indicating dissatisfaction with the thoroughness of the AHC.



Carers felt that a standardised AHC should be offered within the GP contract as a compulsory component and penalties should be given for non-provision. Carers also felt the extension to ID people from 14 to 17 years old was a good thing but also expressed scepticism.

Opinions about best way to ensure that ID people go for AHCs varied from ID people deciding for themselves to AHCs being compulsory. Best interest decisions were recommended involving families, incentives and increasing engagement by increasing training for professionals.

### **Conclusion and recommendations**

The number of people with ID attending and being invited for an AHC needs to be increased. This may be done by increased training, awareness, advertising, correspondence and coordination of and between healthcare professionals, carer organisations and social services etc.

Incorporation of the AHC into the GP contract should be considered so that all people with ID are made aware of its availability.

Standardisation of the AHC is necessary to ensure that the same content is offered to all. This may be taken from “A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability, 2010.” or a similar regime.

Tests which reveal serious diseases should be considered for inclusion in the AHC such as breast and testicle examinations.

A nurse may be used to carry out the AHC without detriment to standards which may “free up” the doctor for other tasks and to cut costs.

Services need to provide person-centred support so that carers feel supported to attend and that environments are safe. Consideration should be given for carers (parents, etc.) of young adults and also of older adults to be given the right to attend with the person they care for. Adequate preparation should be provided to desensitise the person so they are prepared and relaxed with the health checks.

A transformation from reactive responses to health change and health decline to a proactive approach with health checking and health protection and promotion needs to happen.

Intellectual disability (ID) also known as learning disability (LD) in the UK is defined as substantial impairments of intellectual function and social or adaptive functioning present from childhood<sup>1</sup> and is commonly manifested in behavioural problems<sup>2</sup>. People with ID are more likely to have health issues<sup>3,4</sup> and die younger than the rest of the population<sup>4</sup>. Specifically, this manifests itself in women dying on average 20 years sooner and men dying 13 years sooner than the general population<sup>4</sup> and people with ID have also been found to be 58 times more likely to die by the age of 50 than the rest of the population<sup>5</sup>. Hosking *et al.* 2016 reported that the risk of death amongst LD people to be 3-4 times that in the general population which were 6 times as amenable to health care intervention<sup>6</sup>. A report by MENCAP raised the contention that there is institutional discrimination in the NHS against people with an intellectual disability leading to neglect and premature death<sup>7</sup> (MENCAP). Increased life events, female gender, support type, lower ability, more consultations, smoking, incontinence, not having severe physical disabilities and not having immobility were associated with mental ill-health whereas physical ill health resulted in gastric, respiratory and endocrine disorders<sup>2,8</sup>. Also, increased recorded epilepsy, dementia, hypothyroidism and heart failure were features of LD people although decreased recorded ischemic heart disease and cancer were also shown<sup>9</sup>.

These data are mainly caused by inadequate monitoring of health and diagnosis of disease in people with ID<sup>4</sup>. Although patients with ID were around twice more likely to attend the GP than matched controls, consultations were shorter and there was likely to be less continuity of care<sup>9</sup>. There are attempts to remedy this through the implementation of Annual Health Checks (AHC) for people with ID by the NHS under Direct Enhanced Services (DES). These started in 2008-9<sup>9</sup> and currently around 85% of GPs have signed up to AHC under DES (Freedom of Information request (Ref: SDR-291685) although Public Health England gives this figure as 64% of practices as being active in 2013-2014<sup>9</sup>. AHCs have been shown to reduce preventable emergency hospital admissions<sup>10</sup>. However, the uptake of AHC is low. In 2012-13 only 43% of those eligible to receive an AHC received one although there was a large variation ranging from 10.2% to 62.2% although some areas may have reported incomplete data<sup>11</sup>. In 2013-2014 a national coverage of 44% of people with ID had AHCs (Quality and Outcomes Framework for people with LD [QOF])<sup>11</sup>.

## 1 Aims

The main aims of the current study are to discover what factors cause the low uptake of AHC by people with ID and of those who do have AHCs, the level of carers' satisfaction with the health checks. Quantitative data comprised answers to standardized survey questions and qualitative data was collected on carers' opinions and experiences.

## 2 Main Outcome Measures

- i. Percentage of people with intellectual disabilities reported as not having AHC by carers
- ii. Reasons for not having AHC
- iii. Satisfaction with AHC

### **3 Secondary Outcome Measure**

- i. Suggestions for how the Annual Health Check can be improved

### **4 Comparisons/correlations**

- i. Demographic/biographic data of carer compared with whether or not the person with ID goes for AHCs
- i. Gender and intellectual disability level of ID person compared with whether or not the person with ID goes for AHCs
- ii. Whether a doctor or nurse doing AHC affects the person's or carer's satisfaction
- iii. Satisfaction with AHC before and after being told the tests available
- iv. Comparison of number of tests being done against doctor or nurse and against satisfaction levels.

### **5 Qualitative Comparisons/correlations**

- i. Themed comparisons of comments

### **6 Methods**

An e-survey was compiled using Toluna QuickSurveys, which is an efficient and attractive platform. Firstly, a pilot survey was done with 11 respondents who were carers of people with ID and people were invited to criticise and make suggestions about the survey. Both quantitative and qualitative data were collected. An easy-read survey was planned for people with ID but objections were voiced about problems of standardisation because of recall and the spectrum of ID severity and so it was abandoned. Both carers of people with ID who attended and did not attend AHCs were asked to complete the survey to discover reasons for non-attendance. The carers of attendees were given a list of possible AHC tests given by the 2010 RCGP guide<sup>12</sup> which could have been given to assess how comprehensive the AHC was. Satisfaction was assessed before and after the naming of tests through quantitative questions. Comments were invited at the end of relevant questions. The intention of the survey was to gain a wide and varied population of carers for the survey. The survey was launched in April 2014 and lasted a year. The organisations "Learning Disability Carers Community" and "Karen's Page" distributed the e-survey through their websites, Facebook pages and Twitter accounts and the link was reinforced by adding text to encourage participation. The survey was included in the NHS electronic bulletin to CCGs in August 2014 together with a link to a printable edition for carers not able to access the e-survey. The survey was also distributed to various organisations such as county councils and charity organizations many of whom mentioned it on their websites with a link. Survey participants were informed that they could withdraw from the study at any time up until data analysis commenced.

A conference presentation was given to present preliminary data and to encourage delegates to distribute the survey.

## **6.1 Statistical Methods**

In this report, continuous outcomes were summarised with the variables mean, median, standard deviations and range. Categorical outcomes were summarized using counts and percentages.

A primary outcome was the satisfaction with AHC which was rated very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied and very satisfied. To determine the variables associated with AHC, linear regression was used and standard errors and therefore p-values were calculated based on the robust variance estimator because the data are not normally distributed.

For the predictors of whether the person with intellectual disability attended an AHC or not t-tests were used if the demographics were continuous and chi-square tests were used if they were categorical.

## **6.2 Qualitative Methods**

Survey participants were informed that they could withdraw from the study at any time up until data analysis commenced.

### **6.2.1 Code data and prepare data files**

Survey data were anonymised using a unique personal ID code (within the report respondents identified as R number) any names of places or people mentioned in the transcript were removed to ensure that identity was protected.

### **6.2.2 Analyse data and write report**

Questions were analysed in turn. Responses were re-read and themes identified. The 'theme identification techniques' of Ryan and Bernard (2003)<sup>13</sup> were employed to identify themes; the emergent themes presented.

### **6.2.3 Data Analysis**

Data analysis was conducted using thematic analysis (Miles and Huberman 1994)<sup>14</sup>; Richards 2005)<sup>15</sup>; this was achieved by coding individual responses to identify emergent themes and issues. To assist the process Microsoft Excel was chosen as it is easy to present the columns of data for errors and to check spelling and provides a compatible file format to import into Microsoft Word.

### **6.2.4 Coding**

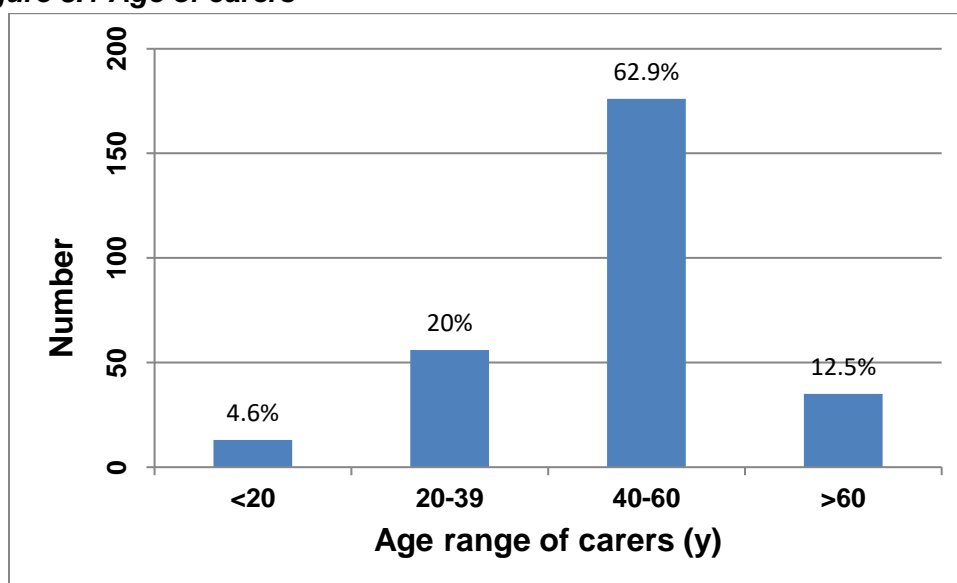
The survey questions were coded in turn so that the patterns that evolved from the transcripts could be identified and would lead to overarching themes and general statements.

## 7 Results

### 7.1 Quantitative Analysis

Once unusable data were eliminated there were 280 respondent data. The proportion of males to females with ID in the study (63% to 37%) was shown to be similar to that in other studies<sup>11;16</sup> and exactly the same as that in the CIPOLD study<sup>4</sup>. Most studies showed that there were more males than females<sup>17;18</sup> diagnosed with ID. The majority of carers were between 40 and 60 years of age; the youngest being 16y and the oldest 71y (Figure 7.1).

**Figure 8.1 Age of carers**



*Figure 7.1: Age of carers*

There is an association between whether a person has an AHC and their relationship with their carer (Table 7.1). In particular, patients who have an AHC are less likely to be cared for by a family member (71% v 90%) and more likely to have a paid carer (20% v 1.6%) ( $p=0.0001$ ).

Whether a person attends the AHC was unaffected by the carer's ethnicity (around 90% of carers were white) or carer's education (Table 7.1).

**Table 7.1: Summary of carer demographics and whether ID person has AHC or not.**

		AHC (n=153)	No AHC/NA/ Other (n=127)	P*
Age of Carer	mean (SD)	47 (14)	46 (14)	0.6365
	median (min, max)	48 (18, 71)	48 (16, 71)	0.8189
Number of people in household	mean (SD)	3 (1)	3 (1)	0.1102
	median (min, max)	3 (1, 8)	3 (1, 10)	0.0402
Gender of carer	male	37 (24%)	36 (28%)	0.4486
	female	115 (76%)	91 (72%)	
	Missing	1	0	
Ethnicity of carer	Asian/Asian British	2 (1.3%)	1 (0.8%)	0.4157
	White	144 (94%)	119 (94%)	
	Black/black British	4 (2.6%)	1 (0.8%)	
	Mixed	2 (1.3%)	2 (1.6%)	
	Would rather not say	1 (0.7%)	4 (3.1%)	
	Missing	0	0	
Relationship to person with ID	Family member	109 (71%)	114 (90%)	0.0001
	Husband/wife/partner	3 (2.0%)	3 (2.4%)	
	Friend	2 (1.3%)	2 (1.6%)	
	Paid carer	30 (20%)	2 (1.6%)	
	Other please specify	9 (5.9%)	6 (4.7%)	
	Missing	0	0	
Education of carer	CSE/GCSE/O-level	32 (21%)	33 (26%)	0.1240
	A levels or equivalent	19 (12%)	22 (17%)	
	Degree/HND	30 (20%)	25 (20%)	
	PG/masters/PhD or equiv	14 (9.2%)	17 (13%)	
	No qualifications	45 (29%)	20 (16%)	
	Other please specify	13 (8.5%)	10 (7.9%)	
	Missing	0	0	

Table 7.1: Summary of carer demographics and whether ID person has AHC or not.

\*From t-test for continuous data, chi-square test for categorical

Female carers comprised the largest percentage 74% (26% male). The highest number of carers comprised family members (223; 80%) of which mothers made the largest number (174; 79%) (Figure 7.2), paid carers totalled 15 (11% of carers). 83% of the people with ID were in the care of the family or friends.

**Figure 7.2 Type of family carer**

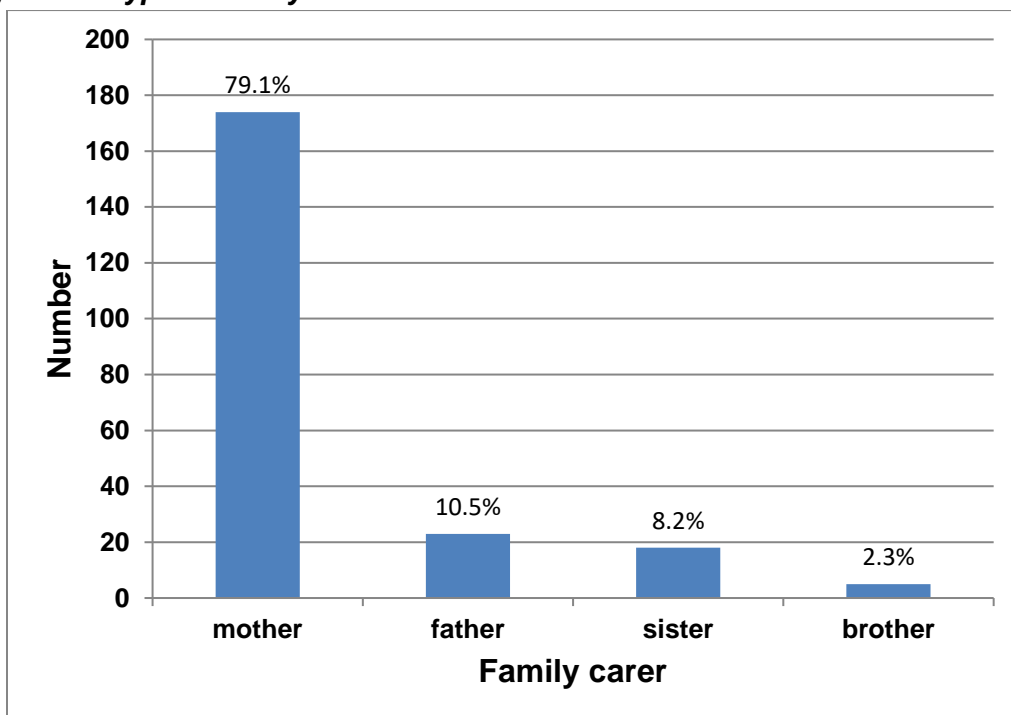


Figure 7.2: Type of family carer

The majority of people with ID were under 30 years old; the youngest were 18y (19) whereas the oldest was 74y (1) (Figure 7.3).

**Figure 7.3 Age range of people with Intellectual disabilities**

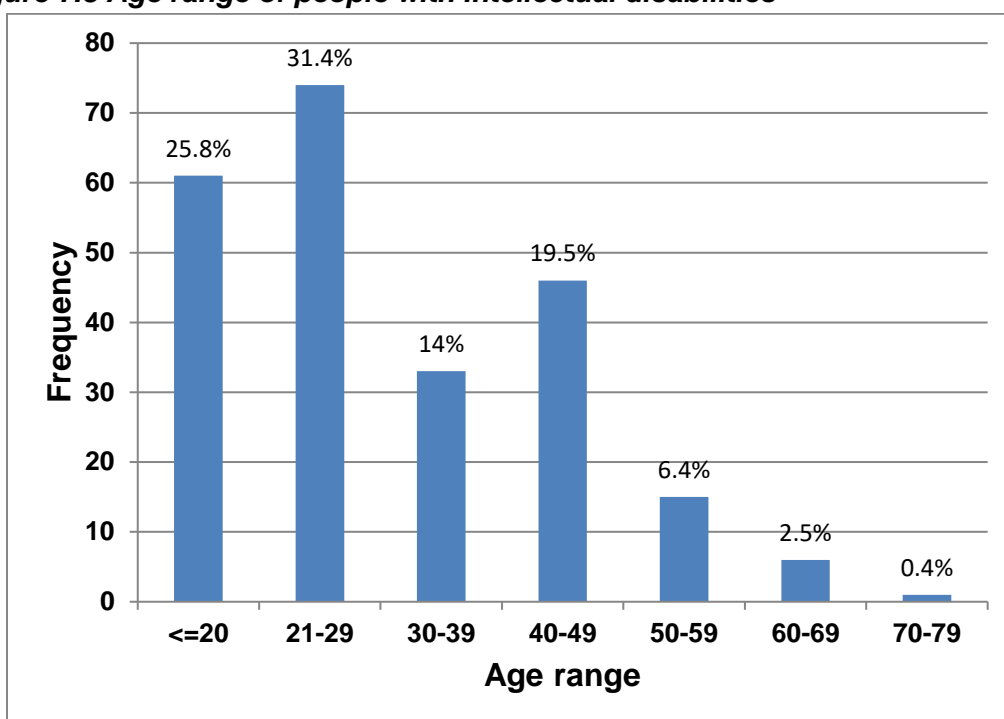


Figure 7.3: Age range of people with Intellectual disabilities

People who had an AHC tended to be slightly older (mean = 34) than those who did not have an AHC (mean = 29) ( $p=0.0037$ ), possibly more likely to be female (42% v 31%;  $p=0.07$ ) and tended to have a lower level of intellectual disability ( $p=0.007$ ) (Table 7.2).



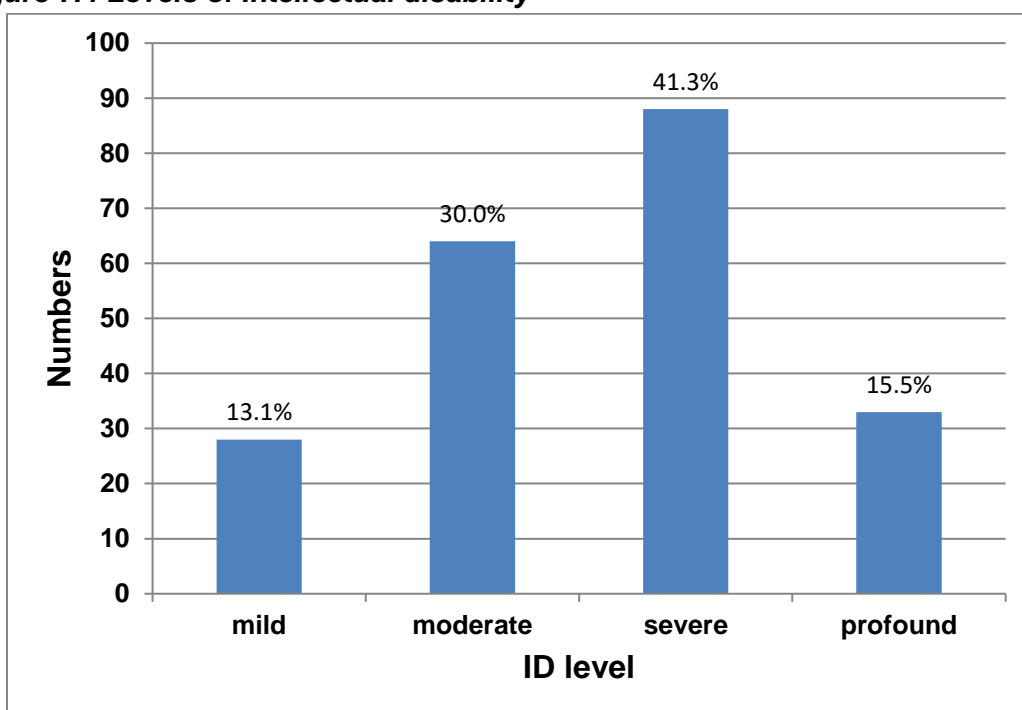
**Table 7.2: Summary of ID person demographics and whether they have AHC or not.**

		AHC (n=153)	No AHC/ NA/ Other (n=127)	P*
Age of person with ID	mean (SD)	34 (13)	29 (11)	0.0037
	median (min, max)	28 (18, 74)	24 (18, 60)	0.0041
Gender of person with ID	male	89 (58%)	84 (69%)	0.0685
	female	64 (42%)	38 (31%)	
	Missing	0	5	
Level of intellectual disability	mild	16 (11%)	12 (9.4%)	0.0007
	moderate	40 (26%)	24 (19%)	
	severe	52 (34%)	36 (28%)	
	profound	23 (15%)	10 (7.9%)	
	don't know/other/won't say	21 (14%)	45 (35%)	
	Missing	1	0	

Table 7.2: Summary of ID person demographics and whether they have AHC or not.

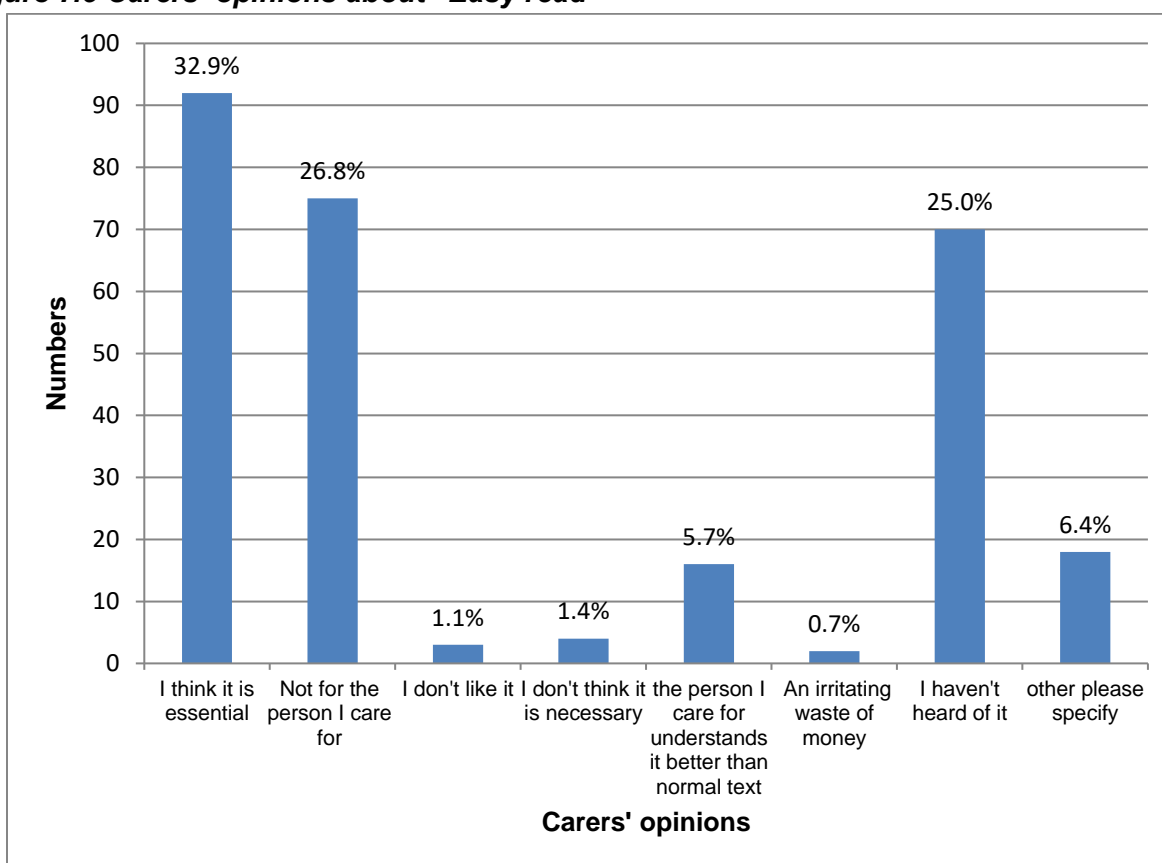
\*From t-test for continuous data, chi-square test for categorical

The highest numbers of people were severely ID (88) and the lowest were mildly affected (28). Percentage levels of ID were: 13.1% mild; 30.0% moderate; 41.3% severe; and 15.5% profound (Figure 7.4).

**Figure 7.4 Levels of Intellectual disability***Figure 7.4: Levels of Intellectual disability*

A slight majority of carers were members of blogs (153; 55.0%). Most people did not receive an AHC appointment letter (147; 52.7%) whereas 106 (38%) did and 26 (9.3%) answered “other” and commented. Moreover, the majority did not get an appointment reminder (139; 62.6%). Almost twice as many people did not receive an easy-read letter as did (90 v 47) but the largest number answered “N/A”: 128 (34.0%; 17.7%; 48.3%). Carers’ opinions on “Easy read” varied from “I think it is essential” (92; 32.9%) to “An irritating waste of money” (2; 0.7%) (Figure 7.5).

**Figure 7.5 Carers' opinions about "Easy read"**



**Figure 7.5:** Carers' opinions about "Easy read"

Carers formed the majority of people who took the ID person for the AHC (65%) of these 19.1% were paid carers.

Only 54.6% (153) of responders reported the person they cared for as going for an AHC (Table 7.3).

**Table 7.3: Number (percentage) of people with intellectual disabilities reported as having an AHC or not by carers**

		Total (n=280)
Does the person you care for go to AHCs?	AHC	153 (55%)
	No AHC	82 (29%)
	N/A	14 (5.0%)
	Other	31 (11%)
	Missing	0

Table 7.3: Number (percentage) of people with intellectual disabilities reported as having an AHC or not by carers

Not receiving an appointment was the reason given for the ID person not attending the AHC by the majority of carers (62; 55%) whereas 31 carers (27%) did not know about the AHC, giving a total of 93 (82%) who were not informed about the AHC (Table 7.4).

**Table 7.4: Reasons given for people with ID not having an AHC by carers**

		No AHC/ NA/ Other (n=127)
Reasons for not having AHC	they refuse to go to doctors	6 (5.3%)
	you didn't receive an appointment	62 (55%)
	you don't see the point	3 (2.7%)
	you think they are healthy enough without an AHC	2 (1.8%)
	you didn't know about the AHCS	31 (27%)
	other	9 (8.0%)
	Missing	14

Table 7.4: Reasons given for people with ID not having an AHC by carers

The majority of AHCs were done by the doctor (86; 43.2%) with the nurse doing 35.7% (71) the rest were shared by doctor and nurse or other health professionals (42; 21.1%). Most carers were happy with the way the person was treated (127; 64.1%) whereas 29 (14.6%) were unhappy with the rest making comments.

Satisfaction with the AHC was assessed on several different criteria: Understanding of the ID person's needs; explanation to the person; explanation to the carer; the pace of the examination; the way the examination was done; content of the examination; thoroughness of the examination; and the care of the person after the AHC. For all the criteria, the majority of carers were very satisfied or satisfied.

Blood pressure measurement was the most widely done test with 75.4% of respondents affirming this followed by weight measurement (71.1%) and the question whether the ID person takes exercise (69.6%). Only 5.9% of respondents were asked about genetic testing and only 6.3% of people with ID had their breasts examined. Moreover, only 10.4% of males with ID had their testicles examined (Table 7.5).

**Table 7.5 Carers' Responses to whether the person with ID was given specific tests or asked certain questions at the AHC**

Test/question	Yes	No	N/A	I did not go into the room	Total	% yes
Did the doctor or nurse ask about genetic testing?	11	145	27	5	188	5.9
Did the doctor or nurse examine the person's breasts?	11	87	70	6	174	6.3
Did the doctor or nurse ask if the person has had a mammogram if female?	16	42	97	3	158	10.1
Did the doctor or nurse examine the person's testicles (if male)?	12	103	0	0	115	10.4
Did the doctor or nurse ask if Down Syndrome is the cause whether thyroid tests are done?	23	42	103	4	172	13.4
Did the doctor or nurse ask if the person has had a smear test if female?	27	45	87	5	164	16.5
Did the doctor or nurse examine the person's ankles?	33	132	18	7	190	17.4
Did the doctor or nurse ask about the cause of the disability?	36	121	28	5	190	18.9
Did the doctor or nurse examine the person's eyes?	36	123	20	7	186	19.4
Did the doctor or nurse ask if the person has fainted recently?	42	112	27	7	188	22.3
Did the doctor or nurse ask if the person has period problems if female?	38	38	77	4	157	24.2
Did the doctor or nurse take a urine test?	56	121	7		184	30.4
Did the doctor or nurse ask if the person has chest pain?	63	92	28	7	190	33.2
Did the doctor or nurse examine the person's ears?	64	100	19	7	190	33.7
Did the doctor or nurse take a blood test?	68	108	10		186	36.6
Did the doctor or nurse ask if the person has urinary problems?	69	89	24	6	188	36.7
Did the doctor or nurse ask if the person has behavioural problems?	70	87	26	6	189	37.0
Did the doctor or nurse ask if the person has fits?	74	81	28	6	189	39.2
Did the doctor or nurse ask if the person has abdominal problems e.g. Constipation, diarrhoea. Bleeding etc.?	77	87	20	7	191	40.3
Did the doctor or nurse ask if the person has had vaccinations	79	80	30	6	195	40.5
Did the doctor or nurse give the person lifestyle advice?	79	83	10	22	194	40.7
Did the doctor or nurse ask if the person has a chronic illness?	78	76	28	6	188	41.5
Did the doctor or nurse ask how well the person communicates?	81	85	19	6	191	42.4
Did the doctor or nurse examine the person's how mobile the person is?	82	78	24	6	190	43.2

Test/question	Yes	No	N/A	I did not go into the room	Total	% yes
Did the doctor or nurse ask if the person has chest/breathing problems?	89	71	23	7	190	46.8
Did the doctor or nurse sound his/her chest?	92	73	18	6	189	48.7
Did the doctor or nurse take the person's pulse?	104	65	18	7	194	53.6
Did the doctor or nurse ask if the person smokes?	117	43	30	5	195	60.0
Did the doctor or nurse take a height measurement?	114	64	6		184	62.0
Did the doctor or nurse ask if the person takes alcohol?	121	42	28	4	195	62.1
Did the doctor or nurse ask if the person eats healthily?	133	39	18	5	195	68.2
Did the doctor or nurse ask if the person takes exercise (if applicable)?	117	47	0	4	168	69.6
Did the doctor or nurse take a weight measurement?	133	47	7		187	71.1
Did the doctor or nurse take a blood pressure measurement?	141	38	8		187	75.4

*Table 7.5: Carers' Responses to whether the person with ID was given specific tests or asked certain questions at the AHC*

There were no significant associations between variables examining satisfaction with the consultation and who conducted the consultation, either before or after being told the tests were available (Table 7.6). There were no significant differences between the nurses and the doctors with regards to patient satisfaction with any aspect of AHC (Table 7.7).

The results in Table 7.8 indicate that knowing what tests the AHC could contain reduces the carers' satisfaction with every aspect of the AHC (all p-values < 0.0001).

**Table 7.6. Summary of satisfaction with AHC before and after being told the tests, for doctors, nurses and others.**

<i>*From chi-square test</i>		Before				After			
		Doctor	Nurse	Other	P*	Doctor	Nurse	Other	P*
Understanding of the person's needs	very dissatisfied	5 (7.8%)	4 (6.6%)	1 (5.6%)	0.5576	10 (16%)	10 (17%)	2 (11%)	0.7228
	dissatisfied	5 (7.8%)	10 (16%)	2 (11%)		7 (11%)	10 (17%)	4 (22%)	
	neither satisfied or dissatisfied	4 (6.3%)	4 (6.6%)	3 (17%)		7 (11%)	7 (12%)	2 (11%)	
	satisfied	13 (20%)	17 (28%)	3 (17%)		16 (26%)	18 (31%)	7 (39%)	
	very satisfied	37 (58%)	26 (43%)	9 (50%)		22 (35%)	13 (22%)	3 (17%)	
	Missing	5	2	1		7	5	1	
Explanation to the person	very dissatisfied	5 (8.2%)	4 (6.6%)	1 (5.9%)	0.6866	8 (13%)	10 (17%)	2 (11%)	0.0616
	dissatisfied	7 (11%)	3 (4.9%)	2 (12%)		9 (15%)	2 (3.4%)	3 (17%)	
	neither satisfied or dissatisfied	4 (6.6%)	7 (11%)	1 (5.9%)		6 (9.8%)	13 (22%)	2 (11%)	
	satisfied	13 (21%)	21 (34%)	4 (24%)		12 (20%)	20 (34%)	6 (33%)	
	very satisfied	32 (52%)	26 (43%)	9 (53%)		26 (43%)	13 (22%)	5 (28%)	
	Missing	8	2	2		8	5	1	



<i>*From chi-square test</i>		Before				After			
		Doctor	Nurse	Other	P*	Doctor	Nurse	Other	P*
Explanation to the carer	very dissatisfied	5 (8.5%)	3 (4.8%)		0.8308	5 (8.2%)	9 (16%)	2 (11%)	0.0385
	dissatisfied	2 (3.4%)	4 (6.5%)	1 (5.6%)		12 (20%)	4 (6.9%)	3 (17%)	
	neither satisfied or dissatisfied	6 (10%)	8 (13%)	2 (11%)		4 (6.6%)	12 (21%)		
	satisfied	14 (24%)	20 (32%)	6 (33%)		15 (25%)	19 (33%)	7 (39%)	
	very satisfied	32 (54%)	27 (44%)	9 (50%)		25 (41%)	14 (24%)	6 (33%)	
	Missing	10	1	1		8	5	1	
The pace of the examination	very dissatisfied	3 (4.8%)	3 (4.9%)	1 (5.9%)	0.3522	6 (9.8%)	8 (14%)	2 (11%)	0.5863
	dissatisfied	5 (8.1%)	4 (6.6%)	2 (12%)		7 (11%)	4 (7.0%)	2 (11%)	
	neither satisfied or dissatisfied	9 (15%)	6 (9.8%)	2 (12%)		8 (13%)	10 (18%)	3 (17%)	
	satisfied	13 (21%)	27 (44%)	4 (24%)		14 (23%)	21 (37%)	6 (33%)	
	very satisfied	32 (52%)	21 (34%)	8 (47%)		26 (43%)	14 (25%)	5 (28%)	
	Missing	7	2	2		8	6	1	

<i>*From chi-square test</i>		Before				After			
		Doctor	Nurse	Other	P*	Doctor	Nurse	Other	P*
The way the examination was done	very dissatisfied	4 (6.3%)	3 (5.0%)	1 (5.6%)	0.7287	7 (11%)	7 (12%)	2 (11%)	0.4652
	dissatisfied	7 (11%)	6 (10%)	2 (11%)		8 (13%)	8 (14%)	3 (17%)	
	neither satisfied or dissatisfied	6 (9.5%)	6 (10%)	3 (17%)		6 (9.8%)	11 (19%)	1 (5.6%)	
	satisfied	13 (21%)	22 (37%)	4 (22%)		16 (26%)	18 (32%)	8 (44%)	
	very satisfied	33 (52%)	23 (38%)	8 (44%)		24 (39%)	13 (23%)	4 (22%)	
	Missing	6	3	1		8	6	1	
The content of the examination	very dissatisfied	6 (9.5%)	5 (8.2%)	1 (5.6%)	0.5855	11 (18%)	11 (19%)	2 (11%)	0.7596
	dissatisfied	8 (13%)	14 (23%)	3 (17%)		13 (21%)	10 (18%)	6 (33%)	
	neither satisfied or dissatisfied	6 (9.5%)	4 (6.6%)	3 (17%)		7 (11%)	11 (19%)	2 (11%)	
	satisfied	14 (22%)	19 (31%)	5 (28%)		16 (26%)	17 (30%)	5 (28%)	
	very satisfied	29 (46%)	19 (31%)	6 (33%)		14 (23%)	8 (14%)	3 (17%)	
	Missing	6	2	1		8	6	1	

<i>*From chi-square test</i>		Before				After			
		Doctor	Nurse	Other	P*	Doctor	Nurse	Other	P*
The thoroughness of the examination	very dissatisfied	6 (9.5%)	4 (6.6%)	1 (5.6%)	0.3379	11 (18%)	12 (21%)	2 (11%)	0.8227
	dissatisfied	8 (13%)	16 (26%)	3 (17%)		15 (25%)	12 (21%)	6 (33%)	
	neither satisfied or dissatisfied	6 (9.5%)	7 (11%)	4 (22%)		4 (6.6%)	9 (16%)	2 (11%)	
	satisfied	14 (22%)	17 (28%)	3 (17%)		18 (30%)	14 (24%)	4 (22%)	
	very satisfied	29 (46%)	17 (28%)	7 (39%)		13 (21%)	11 (19%)	4 (22%)	
	Missing	6	2	1		8	5	1	
The care/handling of the person after the examination	very dissatisfied	5 (8.1%)	2 (3.3%)	1 (5.9%)	0.5420	6 (9.8%)	6 (10%)	1 (5.9%)	0.1754
	dissatisfied	3 (4.8%)	3 (4.9%)			9 (15%)	4 (6.9%)	1 (5.9%)	
	neither satisfied or dissatisfied	6 (9.7%)	11 (18%)	3 (18%)		6 (9.8%)	14 (24%)	3 (18%)	
	satisfied	13 (21%)	20 (33%)	4 (24%)		15 (25%)	20 (34%)	8 (47%)	
	very satisfied	35 (56%)	25 (41%)	9 (53%)		25 (41%)	14 (24%)	4 (24%)	
	Missing	7	2	2		8	5	2	

Table 7.6: Summary of satisfaction with AHC before and after being told the tests, for doctors, nurses and others.

**Table 7.7: Comparison of satisfaction with the AHC when given by doctors or nurses (other has been removed), before and after being told tests**

		Before being told tests		After being told tests	
Satisfaction with:	Who did health check?	Difference in means	P*	Difference in means	P*
Understanding of the person's needs	doctor	Referent	0.1881	Referent	0.2669
	nurse	-0.291 (-0.725 to 0.144)		-0.273 (-0.757 to 0.211)	
Explanation to the person	doctor	Referent	0.9760	Referent	0.3775
	nurse	0.006 (-0.410 to 0.423)		-0.213 (-0.690 to 0.263)	
Explanation to the carer	doctor	Referent	0.4779	Referent	0.2830
	nurse	-0.142 (-0.537 to 0.253)		-0.252 (-0.713 to 0.210)	
The pace of the examination	doctor	Referent	0.6376	Referent	0.3134
	nurse	-0.093 (-0.481 to 0.296)		-0.236 (-0.696 to 0.225)	
The way the examination was done	doctor	Referent	0.6845	Referent	0.1460
	nurse	-0.084 (-0.490 to 0.323)		-0.338 (-0.796 to 0.119)	
The content of the examination	doctor	Referent	0.3431	Referent	0.5531
	nurse	-0.220 (-0.676 to 0.237)		-0.141 (-0.610 to 0.328)	
The thoroughness of the examination	doctor	Referent	0.1803	Referent	0.5962
	nurse	-0.308 (-0.759 to 0.144)		-0.130 (-0.615 to 0.354)	
The care/handling of the person after the examination	doctor	Referent	0.3556	Referent	0.3483
	nurse	-0.175 (-0.548 to 0.198)		-0.204 (-0.634 to 0.225)	

Table 7.7: Comparison of satisfaction with the AHC when given by doctors or nurses (other has been removed), before and after being told tests

\*P-value and difference in means was estimated using linear regression where satisfaction is on a scale of 1-5(1=very dissatisfied, 5=very satisfied)

**Table 7.8: Carer satisfaction with the AHC before and after being told the tests that could be done**

Satisfaction with:	Difference between before and after	P*
Understanding of the person's needs	-0.585	<0.0001
Explanation to the person	-0.462	<0.0001
Explanation to the carer	-0.490	<0.0001
The pace of the examination	-0.343	<0.0001
The way the examination was done	-0.412	<0.0001
The content of the examination	-0.560	<0.0001
The thoroughness of the examination	-0.553	<0.0001
The care/handling of the person after AHC	-0.445	<0.0001

Table 7.8: Carer satisfaction with the AHC before and after being told the tests that could be done

\*\*P-value and difference in means was estimated using linear regression

Table 7.9 presents the summary data and Table 7.10 presents the results of the linear regression models showing that as the level of satisfaction with the AHC increases the mean number of tests conducted increases. These associations are illustrated in Figures 7.6 to 7.13.

**Table 7.9: Summary of the number of tests done for people in each AHC satisfaction category**

		Number of tests within each category				
Satisfaction with:		very dissatisfied	dissatisfied	neither satisfied or dissatisfied	satisfied	very satisfied
Understanding patient's needs	n	31	28	20	46	42
	mean (SD)	6 (4)	10 (6)	13 (6)	17 (7)	19 (6)
	median (min, max)	5 (0, 16)	9 (0, 28)	14 (1, 23)	18 (3, 37)	20 (6, 32)
Explanation to ID person	n	27	21	24	44	47
	mean (SD)	6 (4)	10 (8)	12 (6)	16 (7)	19 (6)
	median (min, max)	6 (0, 16)	6 (0, 28)	12 (1, 23)	15 (3, 37)	19 (6, 32)

		Number of tests within each category				
Satisfaction with:		very dissatisfied	dissatisfied	neither satisfied or dissatisfied	satisfied	very satisfied
Explanation to carer	n	23	25	19	48	50
	mean (SD)	6 (4)	9 (7)	12 (6)	16 (7)	19 (6)
	median (min, max)	6 (0, 14)	7 (0, 28)	11 (3, 23)	15 (1, 37)	19 (6, 32)
Pace of examination	n	23	20	23	47	51
	mean (SD)	6 (4)	10 (8)	12 (7)	16 (7)	19 (6)
	median (min, max)	5 (0, 14)	9 (0, 28)	9 (3, 23)	15 (1, 37)	19 (6, 32)
The way examination was done	n	24	24	23	48	45
	mean (SD)	5 (4)	10 (7)	12 (6)	17 (7)	19 (7)
	median (min, max)	5 (0, 14)	8 (0, 28)	11 (5, 23)	16 (1, 37)	19 (6, 32)
Content of examination	n	32	40	21	43	29
	mean (SD)	6 (4)	10 (6)	15 (6)	18 (7)	20 (7)
	median (min, max)	6 (0, 16)	9 (0, 28)	15 (6, 24)	19 (3, 37)	21 (6, 32)
Thoroughness of examination	n	33	44	15	41	32
	mean (SD)	7 (5)	11 (6)	15 (6)	19 (7)	19 (7)
	median (min, max)	6 (0, 23)	10 (0, 28)	15 (6, 24)	19 (3, 37)	20 (6, 32)
Care after examination	n	19	19	27	51	48
	mean (SD)	6 (6)	8 (7)	12 (6)	16 (7)	18 (7)
	median (min, max)	5 (0, 23)	6 (0, 28)	11 (3, 24)	16 (1, 37)	19 (6, 32)

Table 7.9: Summary of the number of tests done for people in each AHC satisfaction category

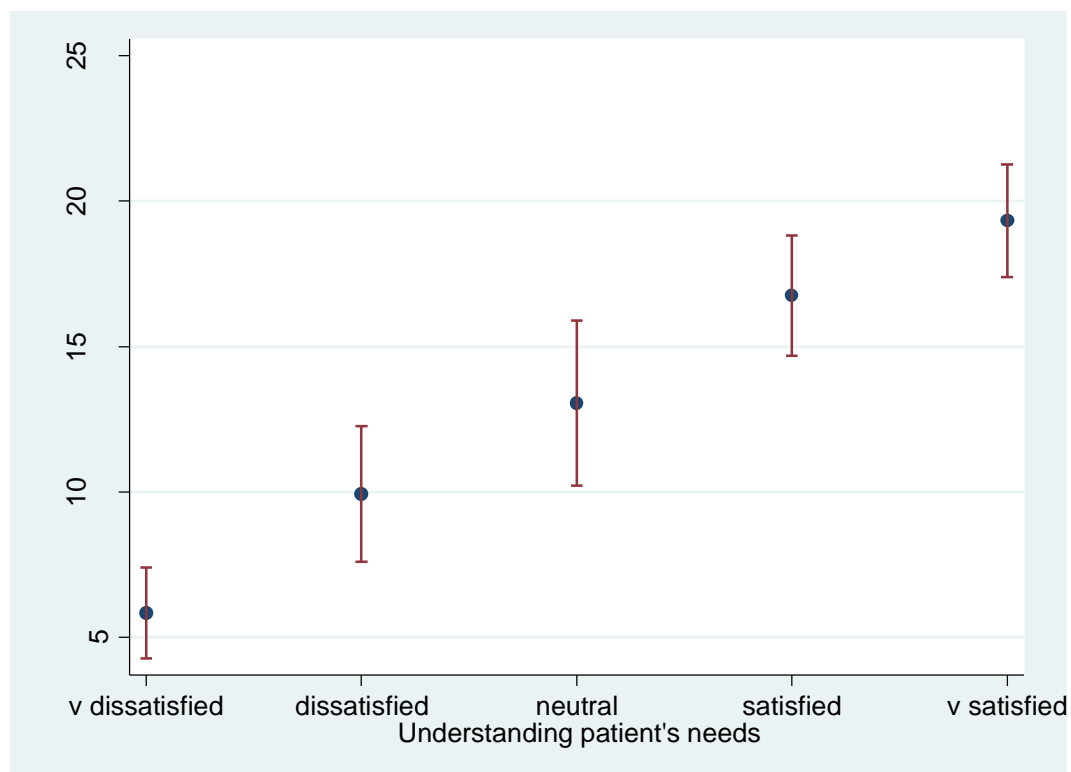
**Table 7.10: Increase in AHC satisfaction (on 0-5 dissatisfied-satisfied scale) associated with the number of tests done.**

Satisfaction with:	slope	P*	Adjusted for time	
Understanding patient's needs	0.114 (0.093 to 0.135)	<0.0001	0.104 (0.085 to 0.123)	<0.0001
Explanation to ID person	0.107 (0.085 to 0.129)	<0.0001	0.099 (0.080 to 0.118)	<0.0001
Explanation to carer	0.106 (0.084 to 0.129)	<0.0001	0.096 (0.077 to 0.115)	<0.0001
Pace of examination	0.1 (0.077 to 0.122)	<0.0001	0.094 (0.075 to 0.114)	<0.0001
The way examination was done	0.102 (0.08 to 0.124)	<0.0001	0.100 (0.081 to 0.120)	<0.0001
Content of examination	0.113 (0.094 to 0.132)	<0.0001	0.113 (0.095 to 0.130)	<0.0001
Thoroughness of examination	0.112 (0.092 to 0.132)	<0.0001	0.111 (0.094 to 0.128)	<0.0001
Care after examination	0.091 (0.068 to 0.113)	<0.0001	0.088 (0.069 to 0.106)	<0.0001

Table 7.10: Increase in AHC satisfaction (on 0-5 dissatisfied-satisfied scale) associated with the number of tests done.

\*P-value is from robust linear regression where the number of tests done in the AHC examination

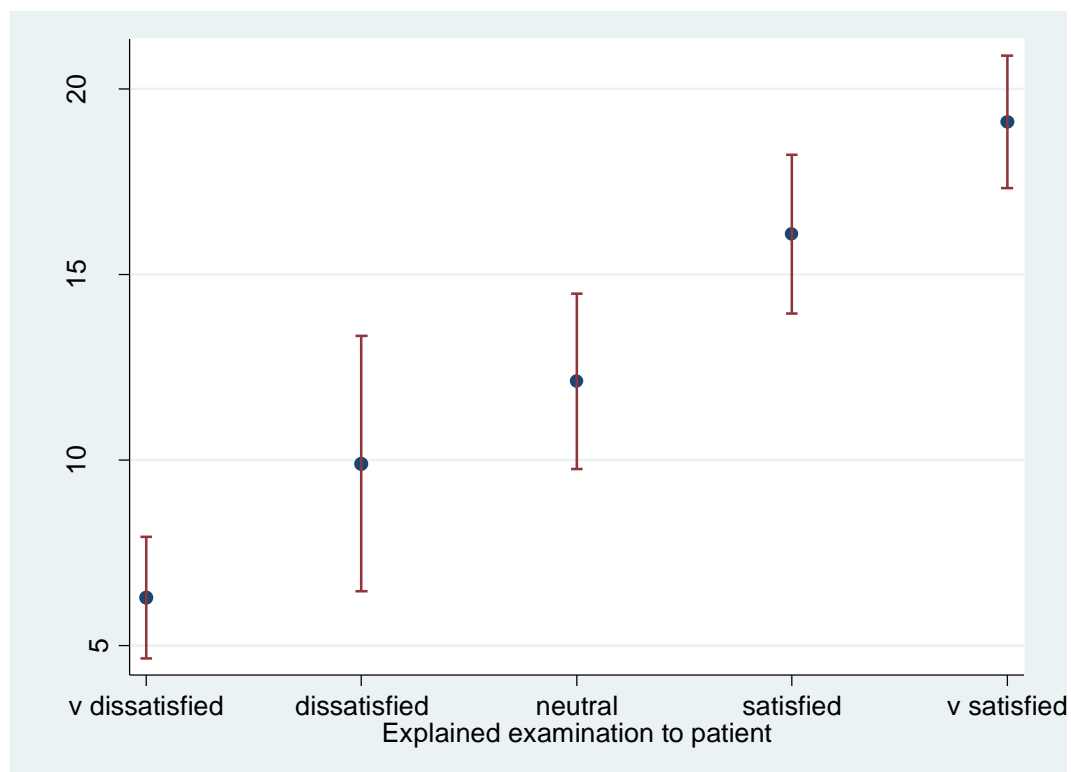
**Figure 7.6: Mean number of tests done for each category of 'satisfaction with doctors or nurses understanding of ID person's needs' with 95% confidence intervals**



*Figure 7.6: Mean number of tests done for each category of 'satisfaction with doctors or nurses understanding of ID person's needs' with 95% confidence intervals*

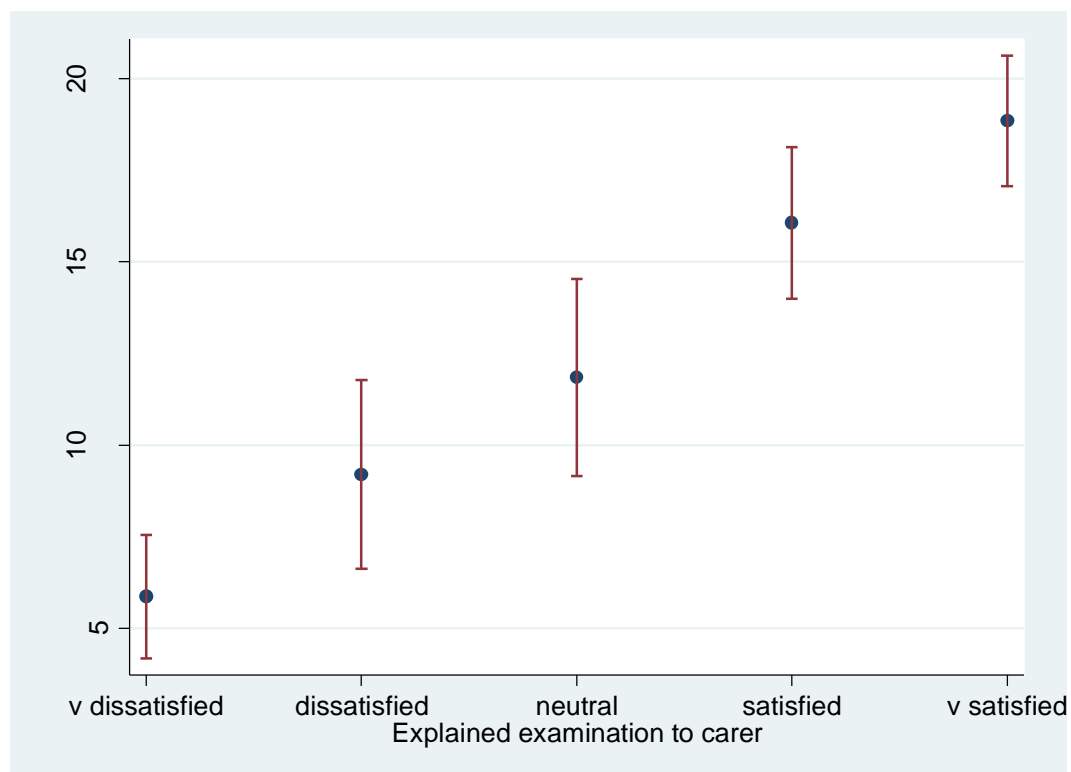


**Figure 7.7: Mean number of tests done for each category of 'satisfaction with doctors or nurses examination explanation to ID person' with 95% confidence intervals.**



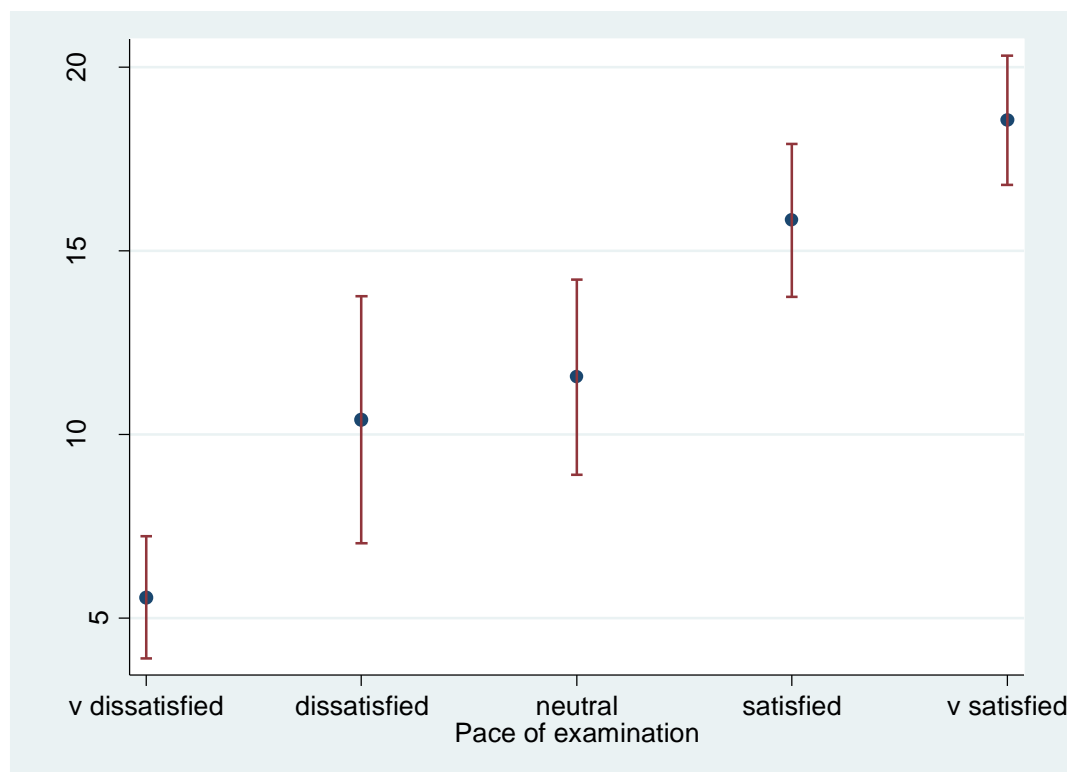
*Figure 7.7: Mean number of tests done for each category of 'satisfaction with doctors or nurses examination explanation to ID person' with 95% confidence intervals.*

**Figure 7.8: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with doctors or nurses examination explanation to carer'.**



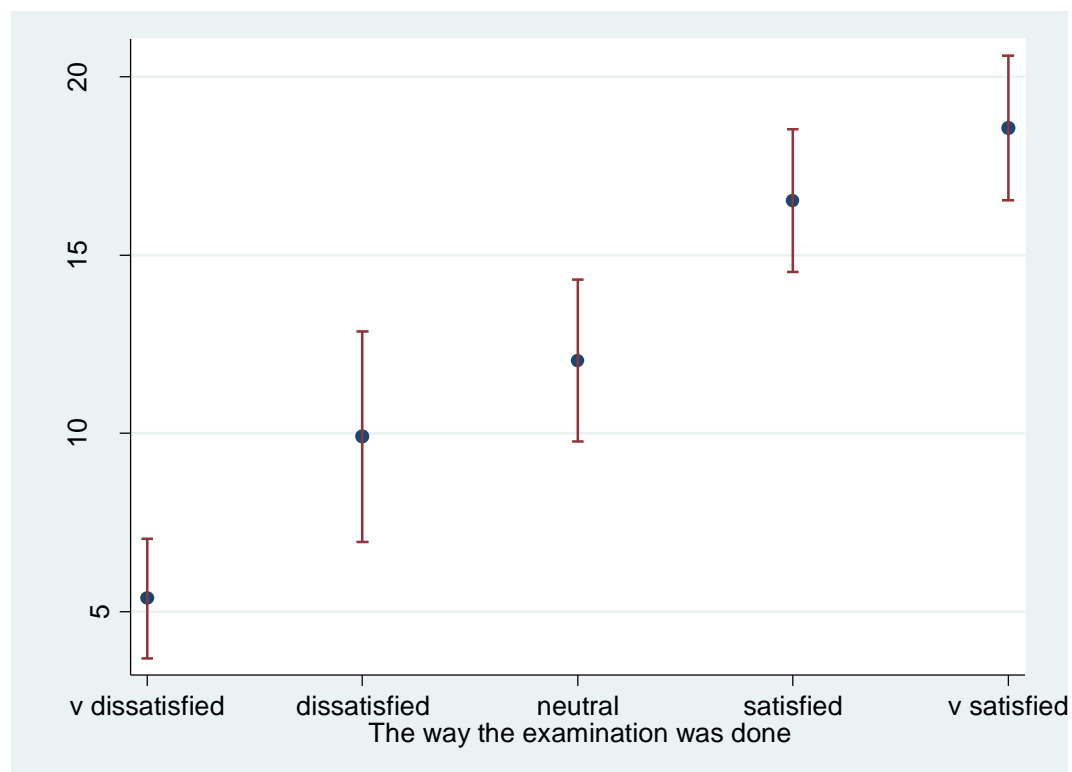
*Figure 7.8: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with doctors or nurses examination explanation to carer'.*

**Figure 7.9: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with pace of examination'**



*Figure 7.9: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with pace of examination'*

**Figure 7.10: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with the way the examination was done'**



*Figure 7.10: Mean number of tests done (with 95% confidence intervals) for each category of 'satisfaction with the way the examination was done'*

**Figure 7.11: Satisfaction with the content of the examination**

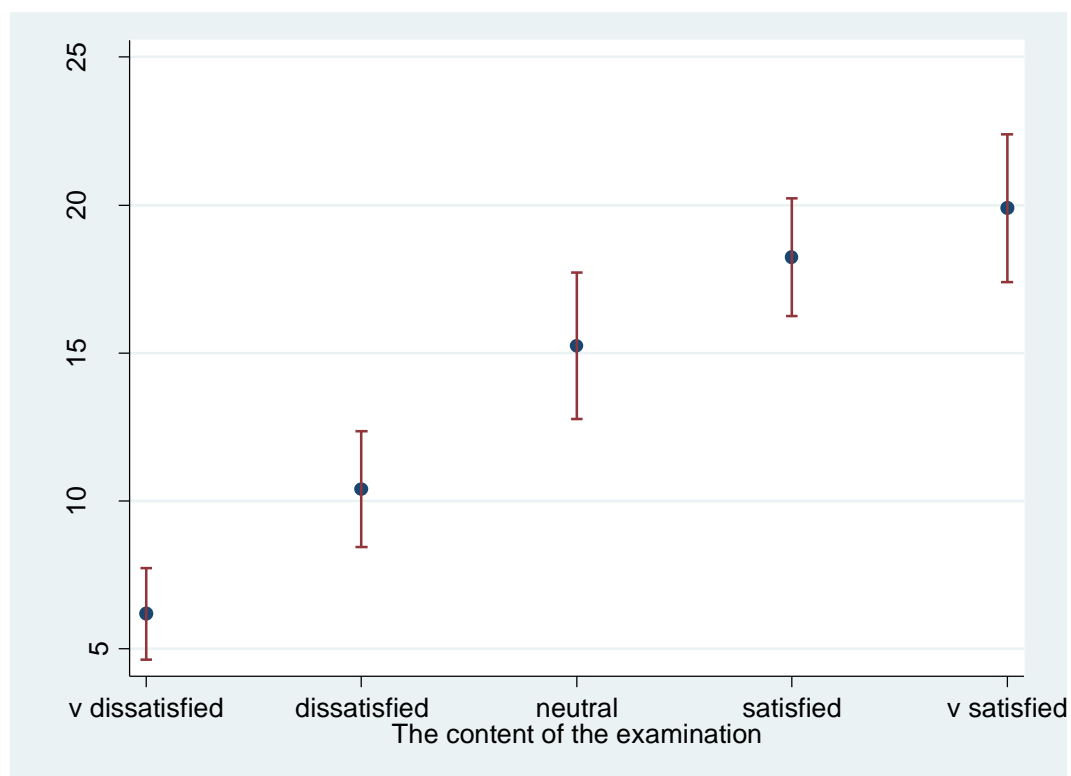


Figure 7.11: Satisfaction with the content of the examination

**Figure 7.12: Satisfaction with the thoroughness of the examination**

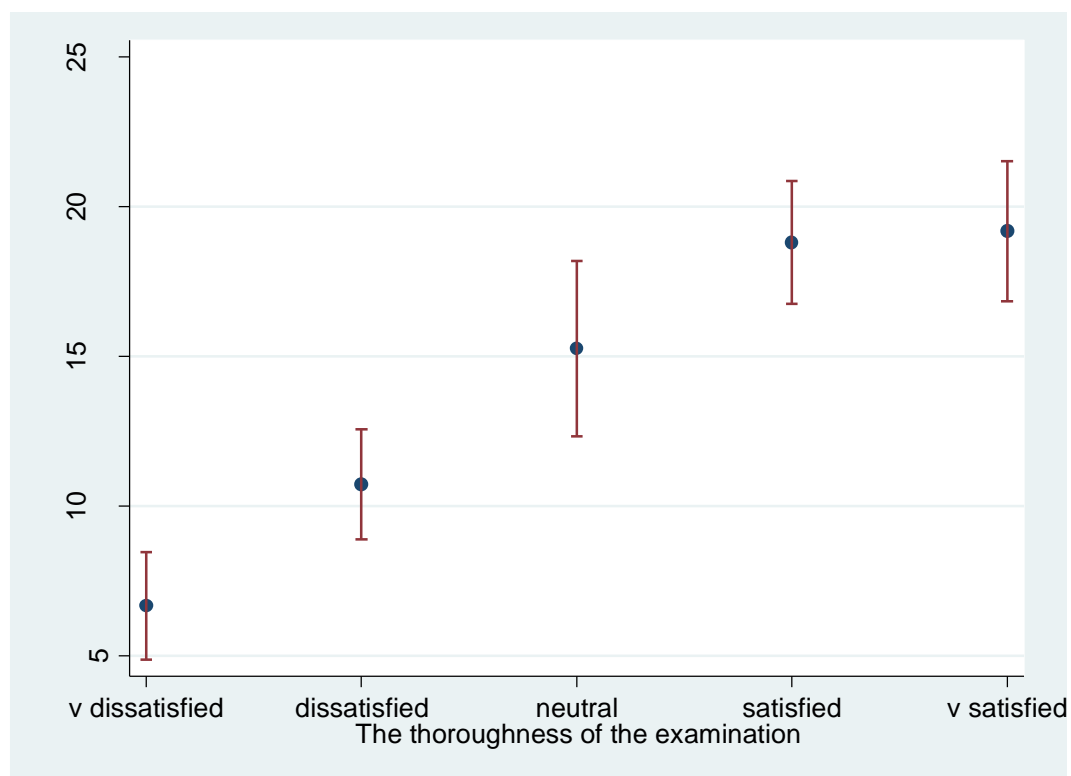


Figure 7.12: Satisfaction with the thoroughness of the examination

**Figure 7.13: Satisfaction with the care/handling of the person after the examination**

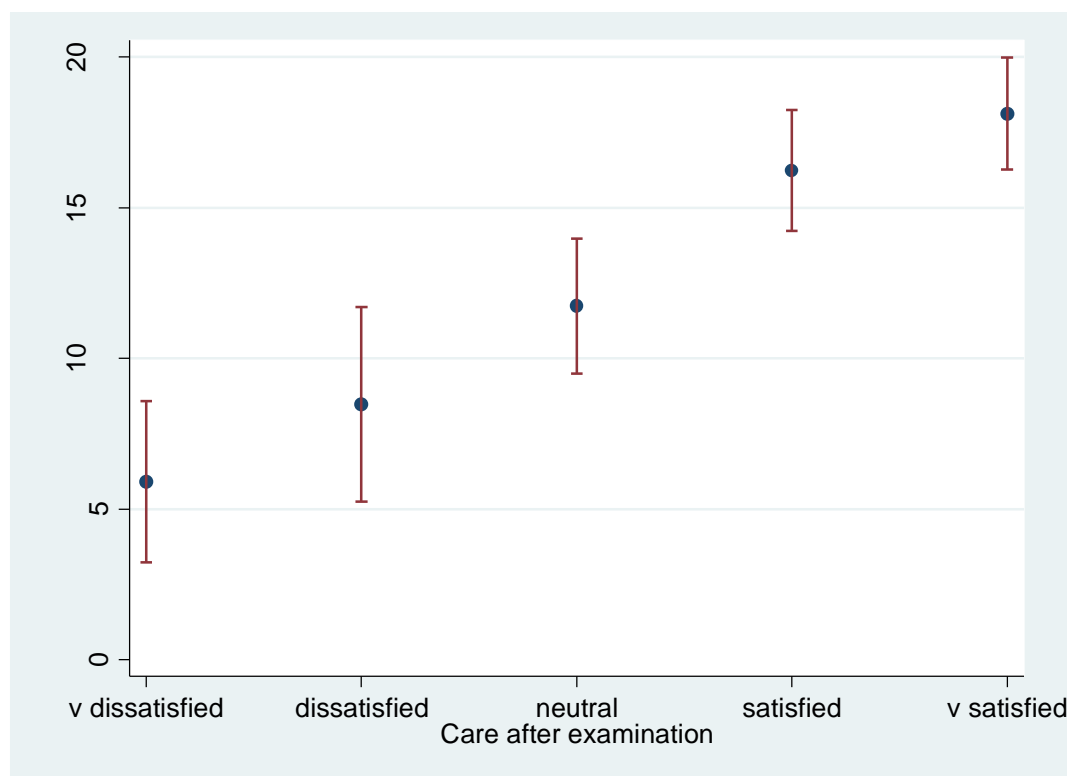


Figure 7.13: Satisfaction with the care/handling of the person after the examination

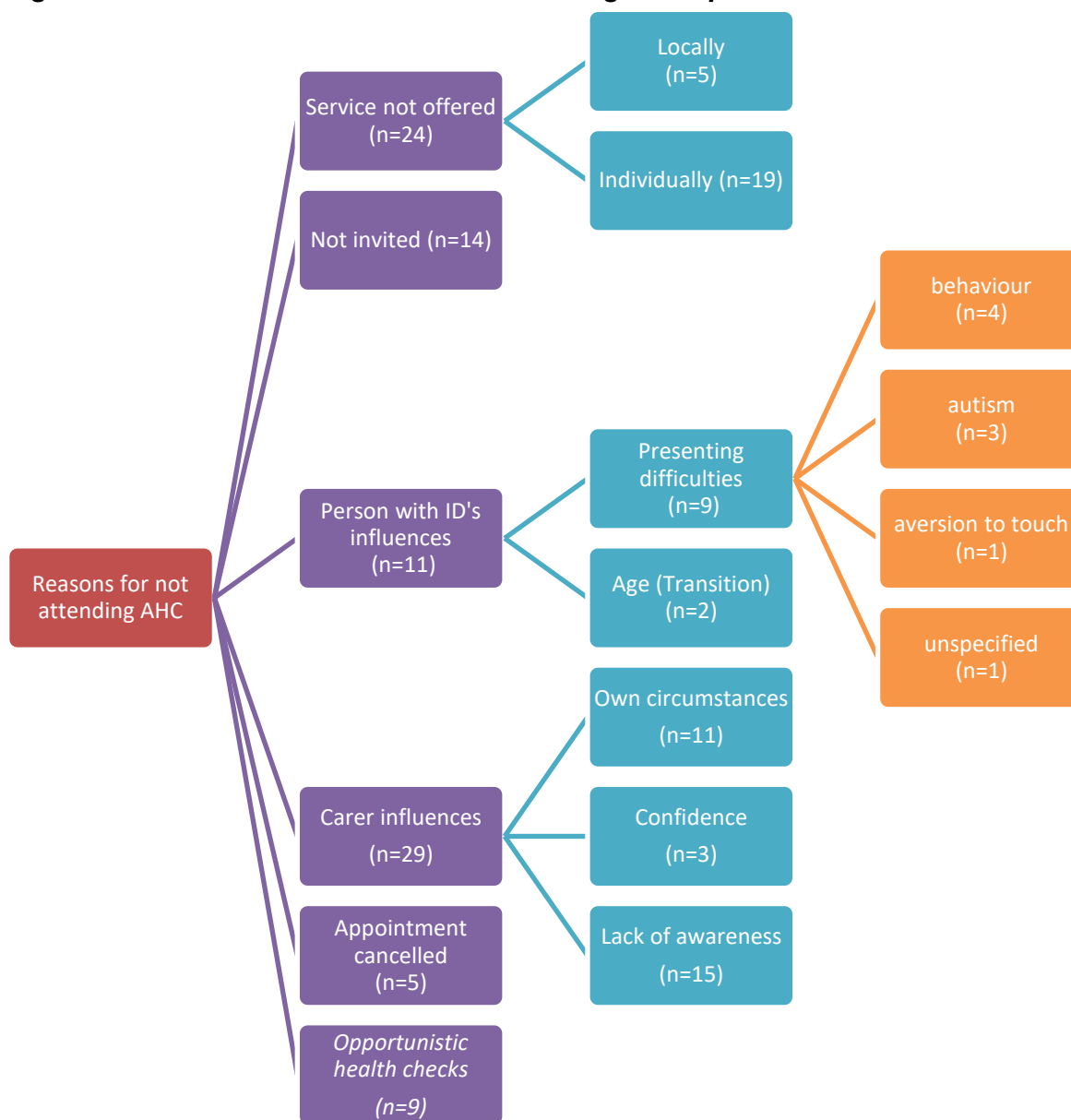
## 7.2 Qualitative Analysis

### 7.2.1 Reasons for not having AHC

(Discussion combined responses from questions Q10, Q13, Q14, Q15, Q16)

Respondents indicated that they have difficulty accessing AHC appointments for a variety of reasons (Figure 8.2.1)

**Figure 7.2.1: Satisfaction with the care/handling of the person after the examination**



**Figure 7.2.14** Satisfaction with the care/handling of the person after the examination



## Service not offered

- **Locally**

One respondent approached their surgery to enquire about availability of health checks and were informed that this was not offered. A similar lack of service was encountered by two other respondents, whilst another identified a lack of service provision for the person they care for through being told:

*“Young people with Asperger's don't qualify for any care services in our authority”.*

Asperger's is not a learning disability however it is included in the study report as the carer reported that the young person has a learning disability.

A respondent stated:

*“I would take my son if it was available though he would need some preparation re: social stories”*

Whereas another was told:

*“Our surgery doesn't believe they have the funding to do these”.*

- **Individually**

The reason not to attend given by a carer was:

*“GP appts are very difficult therefore we avoid going unless there is a problem”*

Carers not understanding the reason for an annual health check not being offered included one carer who expressed uncertainty as to why the appointment was not offered making the assumption that opportunistic health checks are being undertaken so therefore the person did not require an annual health check.

*“Maybe didn't get annual health check as she already goes to doc office for various health issues.”*

Further assumptions were identified by another carer who indicated that their GP didn't offer a health check because the person they care for:

*“does not like to have injections”.*

One person noted that:

*“My daughter, apart from her severe learning disability has many and complex health problems, we see consultants at hospital but not sure why we haven't come up on the GPs horizon.”*

Whilst another stated:

*“Just have prescription reviews every year not had annual health check, but GP asked for blood test”*

### **Not invited**

Although the person's ongoing health is being reviewed it remains a concern for carers that the individuals they care for are not receiving an annual health check.

Six carers indicated that the ID person had not been invited for a health check. One expressed frustration in that the annual health check is not offered and they also have difficulties attaining an annual face to face asthma review,

*“it's being done over the phone with me!!!”*

One person received information about the annual health checks for the first time from their son's GP and confirmation that his name would be included in future invitation requests:

*“We've heard nothing yet”.*

14 carers indicated that the person they cared for had not been invited for an Annual Health Check, comments include:

*“I would like her to, but have not been invited”*

*“no she has NEVER been invited”*

Individuals identified needing to arrange the appointments on behalf of the person with a learning disability, not waiting for invitation. One respondent indicated they had never received an appointment; they arrange the appointment themselves. When another respondent was unable to book an AHC:

*“I book a double appointment”.*

Whilst another person said about the person he/she cares for:

*“she has in the past - if I organise but haven't had 'annual' checks. Currently is it over 12 months since the last one I arranged ...”*

A respondent also indicated a requirement by the carer to follow up referrals stating it is:

*“down to Carer to remind GP who never follows up”;*

He/she expressed their frustration:

*“Don't feel things are followed through. Got standard reminder for medicine review for my son (medication is part provided by GP part by Psychiatrist), when tried to make appt couldn't get one for over 3 weeks!! Don't feel I am supported as a Carer”*

*“The onus is placed on the Carer for this and to organise it for the adult with a disability. Follow up does not happen”*

It is clear from these responses that there is need for a coherent and comprehensive campaign to ensure carers (family and paid) and the individuals they care for are aware of the availability of the AHC. It is also imperative that local service providers of the AHC fulfil their obligations under the Directed Enhanced Service (DES).<sup>19</sup>

Where services are available or may have been offered, reasons for not having an AHC ranged from factors encountered by the individual to those internal and external influences arising with the carer.

### **Person with ID's influences**

- **Presenting difficulties**

There were several responses where the reason for non-attendance at an AHC was indicated as due to presenting difficulties such as:

*“autism, challenging behaviour resulting in physical violence when in a clinical setting”*

*“severe learning difficulties, Severe Autism and behavioural and communication difficulties, refuses to cooperate with health checks.”*

*“Can't cooperate with it due to low mental capacity, SLD, autism and severe and challenging behaviour”*

Reports indicate that the individual was unable to tolerate the interaction during the annual health check, examples include:

*“cannot tolerate the health centre/strangers touching him”*

One respondent identified a tension in attending the GP appointments:

*“My son doesn't like going to the doctor, but will if I tell him he must for his own sake”.*

For some, the focus on attending the doctor is for an intervention when one is unwell. A shift to preventative health care appears difficult for some for instance, one carer indicated that the person they support has an:

*“issue in understanding going to the doctors if not unwell”.*

A respondent recounted a particularly difficult experience which influences future decisions regarding attending AHC:

*“last time I took my son for a check-up when he was well after a few mins he decided he wanted to leave and I made the mistake of putting myself in the way to prevent him from leaving. The challenging behaviour kicked in and I was slapped, kicked and had my hair violently pulled had to end up pinning him up against the wall till he calmed down and*

*stopped lashing out but as soon as I released him he was out of the door and I had to follow to make sure he and others remained safe”.*

Because of the behaviour this parent considers that the son:

*“needs to be ill before going to doctors as that what he understands doctors are for”.*

While another parent implied that there is a change occurring for their daughter in their situation:

*“She goes but it is becoming more difficult to get her to any medical appointments”.*

The exact nature is unspecified, and this may be a change for the carer or a change for the individual. Furthermore, another carer indicated that the AHC was:

*“Offered in school, but not through GP, did not take up in school as did not want to expose to unnecessary routine medical checks”.*

The priority here is for services to provide person-centred support so these carers and others in similar situations feel supported to attend and that environments are safe. Adequate preparation needs to be provided to desensitise the person so they are prepared for and are comfortable with the health checks, but more importantly a shift needs to occur which moves from reactive responses to health change and health decline to a proactive approach with health checking and health protection and promotion approaches.

- **Transition from childhood to adolescence**

Bureaucracy at time of transition was a key concern from one carer:

*“I think my son is stuck in NHS/SOCIAL services bureaucracy at transition so any triggers for an annual health check do not function for him”.*

Change in eligibility, identified by one carer who stated:

*“I was told that because my daughter was entered for 2 GCSE's (Art and ICT which she didn't pass) she was no longer considered to be under the learning disability team, so I'm not sure how she is characterised by GP's”.*

A further theme arising in responses to this question was the impact upon attendance from the carer as supporting person.

### **Carer influences**

- **Own circumstances**

One carer expressed it is:

*“too difficult”;*

While another stated:

*"I am too physically disabled to take her. She won't talk to strangers and doesn't trust Dr's, and misinterprets a lot of what is said or asked of her (which makes her upset)."*

One respondent identified a reliance on the paid carer and non-attendance due to staff non-acceptance of the appointment:

*"Their staff didn't accept the offer and we weren't aware they weren't taking him".*

Whilst another explained that in their role caring for both a dependent child and a dependent partner, attendance at the AHC is:

*"yes and no",*

One person explained how a previous 'experience' has influenced their son's attendance at AHC:

*"If it wasn't for my wife and myself insisting he goes he would not go".*

Eligibility for the AHC is based on the individual presenting with having a learning disability. A carer faces a personal challenge, stating:

*"that I do not want to tell the doctor in front of my daughter that she has got learning difficulties as I think it would be bad for her self-esteem, and that is poor enough as it is."*

Another respondent implied that the person does not attend due to their own availability:

*"No support for this other than me".*

Proximity to the person is a significant challenge as a main carer, living 200 miles away, recalled a detailed personal story expressing his/her son's (and son's wife's) vulnerability and complex health needs. The parent's job is supported through a:

*"Solicitor..... and an objective assertive care manager".*

Awareness of the ID person's own health is also critical:

*"when he is ill I have to accompany him to all appts ...It has to get bad before my son will advise that he feels un well" (R156).*

One respondent (a relative) alleged that there had been catastrophic outcomes for the person with ID from non-attendance of the AHC and profound dissatisfaction with the service, citing examples where paid care staff had not acted on the invitation for the AHC:

*"care home staff ignored 3 invitation letters my brother was removed from the gp register"*

The relative then inferred that this inaction had fatal consequences for his/her brother. It was also implied that the statistics for the surgery would show their percentage of completed annual

health checks, rather than for those removed due to non-attendance, regardless of why this occurred:

*“the gp surgery stats looked better”.*

Another respondent stated that the AHC was:

*“totally inaccessible to him”,*

Unfortunately, this respondent did not elaborate on her or his response so it is not possible to determine the meaning behind the response.

- **Confidence**

One responding carer appeared particularly dissatisfied with their experience and questioned the expertise of those providing the health check:

*“I would not take my mainstream children unless they were unwell, and feel the exposure to routine checks is not needed especially if there is no real level of expertise and understanding, if your young person has known the G.P. well then it may be a different story, we attend for medication review that takes 2 mins. Not sure routine health checks offer a lot otherwise unless by skilled team to cover all angles, benefits, wellbeing support”*

However, another person appeared unconcerned that the person they care for has not been invited for AHC, indicating:

*“... is not on any medication and health is good for a person of 24”*

While a parent indicated that his/her daughter is:

*“generally pretty healthy and hasn't seen a doctor for years”,*

However, they express concern about the time to make appointments:

*“To get an appointment takes around two weeks”*

He/she also expressed concern that staff are not aware of the person needs before the visit:

*“If she did have to go down I doubt that they would even realise she had moderate learning difficulties and was on the autistic spectrum unless I told them when I went with her as they never read anyone's notes very thoroughly when you do visit”.*

- **Lack of awareness**

There was uncertainty in responses with some respondents demonstrating a lack of distinction between Annual Health Checks (AHCs) and Health Action Plans (HAPs).

Fifteen carers indicated a lack of awareness regarding the AHC. One person expressed incredulity:

*“I cannot believe I’ve never been informed that my son should have annual health checks”*

Two parent respondent carers, whose children are in transition to adulthood had not been informed of the AHC as part of this transition point in life. With this recent awareness one respondent indicated that he/she would be contacting the GP to arrange the AHC for her daughter:

*“She has severe Id and is non-verbal. When she is ill or in pain she self-harms as she cannot tell us so hopefully annual checks will help keep her healthy and happy”.*

One respondent was aware of the AHC, but unaware that they should be initiated by the GP. Health checks were secured through:

*“... myself contacting learning disability health team and now a LD nurse is involved with by son’s health checks”.*

For those who indicated recent awareness, one became aware through the GP, while two became aware through social media.

### **Cancelled appointments**

A further predicament arose where the appointment had been offered to the individual or had been arranged by the respondent/carer and it did not go ahead due to cancellation by someone other than the respondent. One respondent identified that the paid carer had cancelled and rearranged the appointment; while two respondents noted that they had cancelled and rearranged an appointment. The appointments may have gone ahead but not as originally intended.

One carer reported:

*“Nurse rang 9.30am with appointment for 4pm!!! This was just out of the blue and we were already out on activities all day.”*

Short notice appointments may be of benefit to some individuals however, given the ‘punctuation’ expressed within this response it would be reasonable to believe that this carer did not appreciate the short notice.

One respondent provided an indirect response to the question. He/she did not comment on his/her inability to attend a scheduled appointment but provided commentary on the requirement for the person to arrange their own appointment:

*“the letter invited my son to make an appointment from the outset, they didn't set the appointment date or time, they invited us to.”*

This approach by the service may prove problematic if the person is unable to make their own appointments.

### **Opportunistic health checks**

Although the survey asked about reasons for not attending annual health checks, 4 respondents recounted situations where the health check occurred but was not specified as an 'AHC'.

Examples given by respondents of health matters checked annually include: asthma reviews, blood tests, flu jabs and medication reviews but it was not clear if opportunistic health checks took place at the same time.

Respondents reported benefit from opportunistic health checks during other routine appointments:

*“he sees the Doctor quite often with medical issues anyway.”*

Another respondent noted that the person with ID only undergoes prescription reviews. While two respondents recounted positive experiences indicating that their GP is approachable and will provide any check on request and initiates referrals to other services as required. It is relevant to note that the contact with the GP was initiated by the carer rather than the GP.

Alternative locations are sought where possible:

*“less stressful/upsetting best done at home”*

*“Offered in school, but not through GP, did not take up in school as did not want to expose to unnecessary routine medical checks”*

Clearly from the responses it is evident that the carer plays a key part in the success of the AHC for those individuals who require support to attend. Recognising the value of the AHC, preparing the person to attend as well as their availability and ability to access the appointment are all central to the appointment's success.



## 7.2.2 Satisfaction with the Annual Health Check

(Responses from open text for questions Q17)

**Figure 7.2.2: Responses when asked how satisfied respondents were with the AHC**

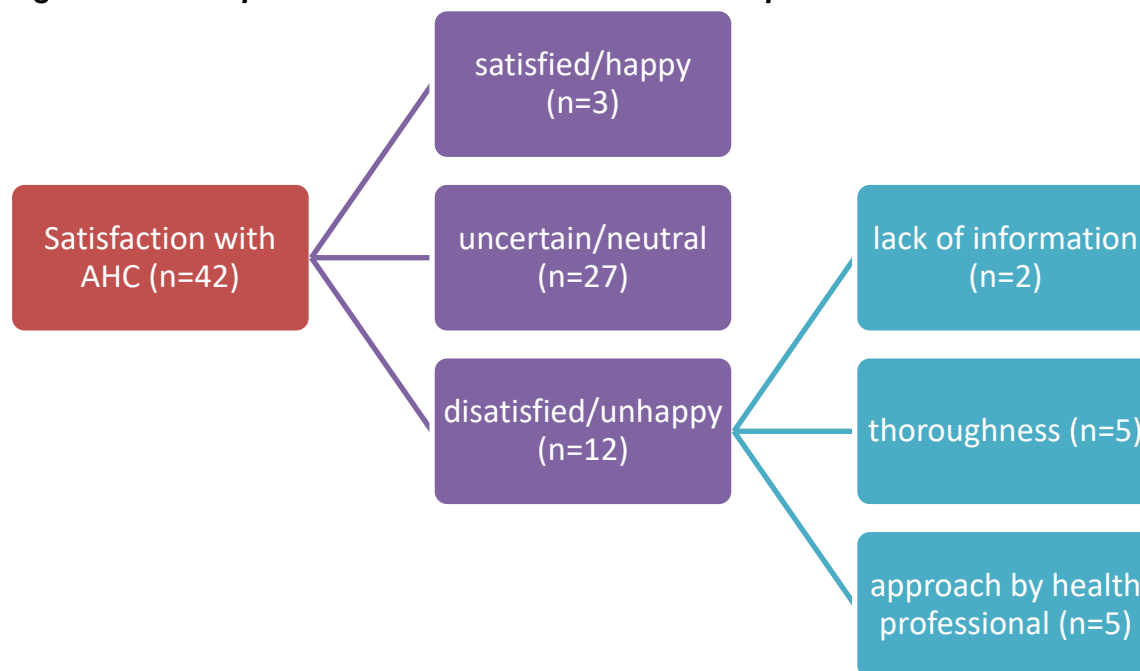


Figure 15: Responses when asked how satisfied respondents were with the AHC

There were 42 respondents to this question however, only fifteen indicated experience of the AHC upon which they could report satisfaction.

### **Satisfied/happy**

One carer expressed that they were happy with the way the person they care for was treated at the annual health check but no further detail was provided. While another indicated they were happy with the AHC but with restraint:

*“yes, but it is not in depth enough, not enough comms between professionals”*

and yet another expressed satisfaction with the AHC but said:

*“it wasn't really a health check”,*

unfortunately, there was no further detail provided to indicate the type of check undertaken.

### ***Uncertain/neutral***

Of the remaining 18 respondents identified, the person they supported did not have an AHC. However, it is uncertain from the responses to this question (Q17) whether this means the individual was invited but did not attend or was not invited to attend an AHC. One respondent explained:

“unable to do the health check because of his activity level”

However, this respondent did not indicate the level of satisfaction regarding this experience.

Another respondent explained the AHC did not occur as:

“He does not like needles”.

From these encounters it is evident that care expectations are a factor in the level of satisfaction experienced. The need for detailed information about the components of the AHC is clear and would alleviate potential anxieties prior to and during the AHC. It would also provide carers with greater clarity in what to request where they feel the checks fall short. This information would also be of benefit in assisting to prepare the person who is attending the AHC so they know what checks and tests will be part of the AHC and aid the identification of opportunities for desensitisation.

A further aspect for attention is the interpersonal dynamics of the individual professionals delivering the AHC. This is essential for effective communication and participation by all concerned.

### ***Dissatisfied/unhappy***

Several other respondents identified dissatisfaction with the experience, a combination of the following:

The check was not considered thorough enough by three respondents:

*“more checks .... are needed my opinion it was very basic”,*

*“It was done by one doctor without my knowledge and from what I could gather was very superficial”.*

- **Lack of information**

Lack of information about the health check led to dissatisfaction for one carer who stated:

*“I think as a carer I should receive some guidelines as to what to expect”;*

similarly, another respondent noted:

*“Not sure what was meant to happen, so have no gauge of what “should” be done”.*

- **Approach by health professional**

The approach by the health professional was cause for comment with one respondent expressing that the AHC:

*“seemed to be a bother for the nurse”;*

while another carer expressed that there was:

*“not much empathy with learning disabled person”*

However, during the health check a positive experience was expressed by another respondent who indicated the person was:

*‘treated well’*

but stated from their perspective the quality of the check was better with the:

*‘previous doctor’.*

Of particular note, two carers stated:

*“we are getting to scared to even go to the Dr for basic care”.*

For health checks to be effective services must ensure that people are fully informed so they can make an informed decision to attend the check, but most importantly people must not be fearful and feel safe and confident in the service offered.

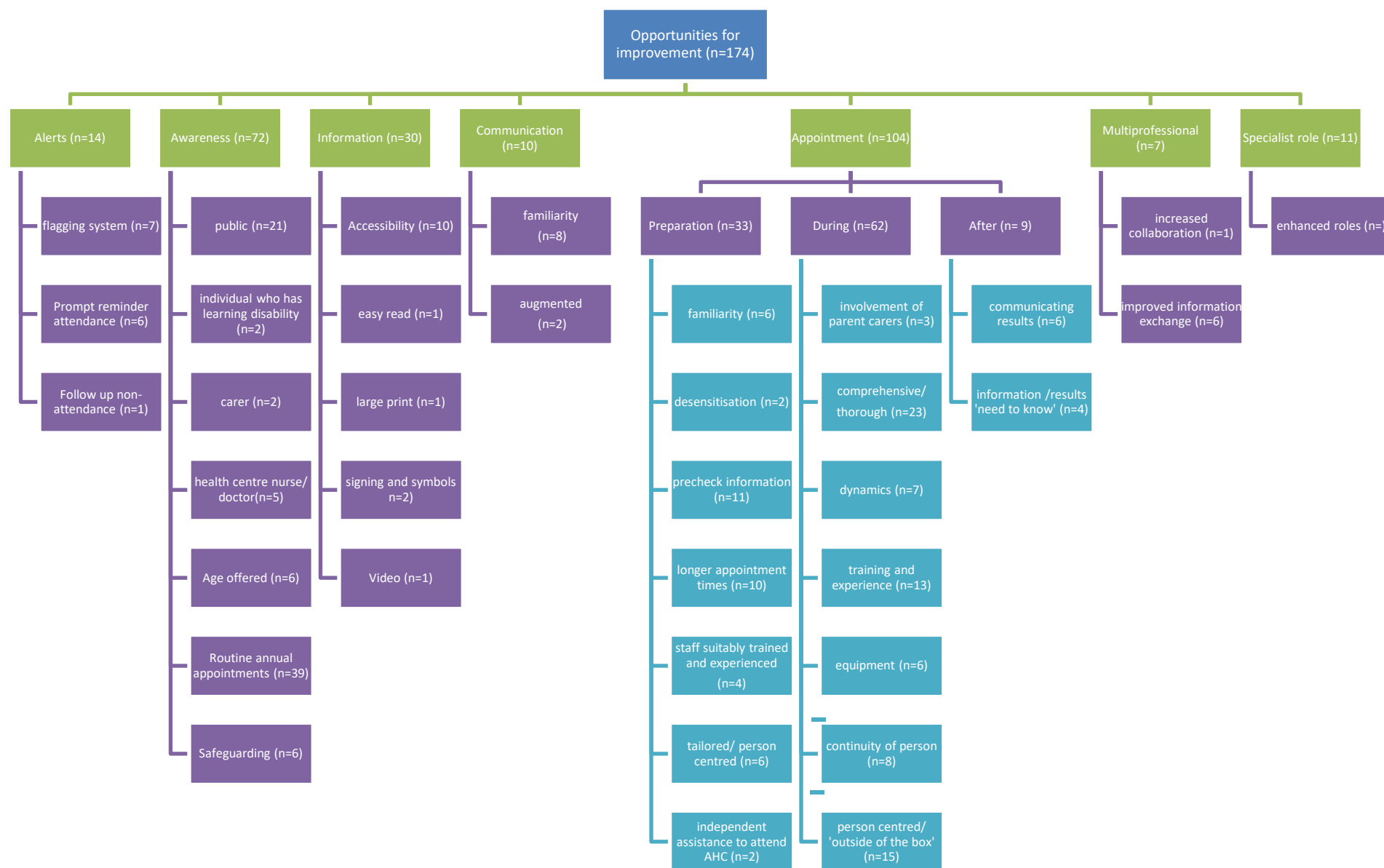
### **7.2.3 Suggestions by respondents to improve the Annual Health Check**

Q30. How do you think Annual Health Checks for People with Learning Disabilities can be improved?

202 respondents; Opportunities for improvements = 174; No improvement suggested = 16

Null = 12

**Figure 7.2.3: Diagram to show themes in respondent suggestions which may give opportunities for improvement for the AHC**



**Figure 7.2.3** shows themes in responses which may reflect steps for improvement in the AHC from initial identification and raising awareness through to the recommendation for specialist practice.

### **Alerts**

Three respondents made suggestions for identifying the person eligible for the AHC through 'patient flagging system' and 4 respondents suggested the provision of an annual appointment reminder system led by the health provider.

- **Flagging system**

Develop an accessible process for inviting the person for the appointment e.g.:

*"start with easy read appointments, follow up if no appointment made (appoint a contact so this can be followed up if needed), (my daughter ignores letters), GP/nurse to send post appointment letter to summarise any issues so anything raised does not get forgotten"*

- **Prompt reminder attendance**

Two respondents' comments included:

*"prompting patient when check is due either by telephone or text"*

And one suggested:

*"copy of appointment letter sent to carer"*

And two respondents suggested:

*"for those in supported/ independent living there should be a reminder on the letter to show it to the staff supporting the person so the appointment does not get missed."*

- **Follow up non-attendance**

Likewise, providing 'encouragement' to attend AHC with follow up with those who do not take up the AHC was suggested by one carer.

### **Awareness**

- **Public**

Suggestions were made by 21 respondents about raising awareness of AHCs to the public at large and specifically to the learning disability population in particular awareness raising e.g.:

*'to family members'*

- **Individual who has ID**

Two respondents suggested that the GP should have a particular role in raising awareness with Patients. In addition, the need to raise awareness of the AHC and their role as GPs to provide AHCs, was reported by 5 respondents.

- **Age offered**

The most suitable time to offer AHCs was addressed by several respondents. One carer suggested that this is offered at first point the person is recognised as having an Intellectual disability whereas 4 respondents suggested that the AHC should be offered to Young\* people (One carer suggested that it should happen from the age of 16), (\*young is not defined).

- **Routine annual appointments**

Ensure 'routine annual' appointments for AHCs are offered or given to all people who have an Intellectual disability was suggested by three respondents, whereas 36 respondents said it should be "as standard practice".

Two respondents suggested that the AHC should be made:

*"a statutory duty".*

Surgeries/doctors willingness to undertake the AHC was raised as a concern by one carer. Two carers said that:

*"respect given by surgery staff towards patients and carers instead of applying bullying/harassing tactics in order to earn their £100 per check"*

And:

*"GPs should be forced to offer every qualifying patient one every year it should not be optional (enhanced scheme)".*

- **Safeguarding**

One respondent proposed that:

*"Doctors should be held accountable for not providing them. If staff or families don't support the person to attend a safeguarding alert should be made. CQC should audit and inspect quality of annual health checks. GMC should be involved when standard is not acceptable".*

### **Information**

Seventeen respondents indicated that individuals who have a learning disability, their patients and carers need to know what to expect from health checks including two who suggested 'family members'. One extended this need for information about the AHC to services/clubs and other activities/places where the person who has a learning disability attends and or receives support.

- **Video**

One respondent suggested:

*"Provide a social story template and have a role play video on you tube/available to watch to help prepare the person before they go".*

Another recommended that a:

*"copy of what the annual health check should encompass"*

Should be sent to every person who has a learning disability and also to every carer of a person who has a learning disability.

- Easy read, large print, Makaton symbols, pictorial aids

Accessibility is alluded to in many examples and specifically indicated by 10 respondents

(Makaton - communication approach is subject to copyright so cannot be taught freely. Similarly, many symbol systems are also copyright. We are commercialising communication and therefore restricting its use.)

One respondent reported on his/her use of accessible documentation completed during consultation, with another referring to a specific document he/she had used as being beneficial namely, the:

*"Down Syndrome Association Health book".*

Another carer indicated that accessible information would be valuable for "PMLD better understanding of all needs".

### **Communication**

Effective communication is essential according to three respondents.

- **Familiarity**

Several respondents recounted experiences where communication has been unsuccessful. One reported that:

*"On the few occasions my daughter has had to be seen by drs/ nurses it is clear they have no idea of how to relate - no direct contact to her (only me, as though she isn't there!), no time given for her to process what is happening or time for her to give her answers..."*

One carer cautioned that the person carrying out the AHC should:

*“Actually talk to the person even if the person does not respond. No response does not mean they aren't listening.”*

The person carrying out the health check also needs to look out for non-verbal communication, examples included:

*“unable to talk but can nod yes or no”.*

*“I think doctors/nurses should listen to the person, or in my daughter's case as she does not speak they should listen to the parent/carer”*

*“speak to the individual”*

- **Augmented**

Two respondents suggested:

*“...nurses should know Makaton and should use symbols with their patients” R280*

*“pictorial aids”*

To explain the procedures.

Furthermore, one carer indicated that it is important to ensure the person who has a learning disability is the focus of the appointment, whereas another suggested that pairing with other family member appointments should be avoided.

## **Appointment**

### **Preparation for the AHC**

- **familiarity**

There were 6 suggestions for AHC preparation included familiarising the person with process before the health check and two for providing the opportunity for desensitisation if necessary.

- **Pre-check Information**

A pre-check questionnaire was suggested by one respondent (however, another cautioned against too much reliance on the pre-check questionnaire and suggests a more thorough health check procedure).

Six respondents suggested a checklist of checks/outline process. One carer took this further with the suggestion that the checklist could be used by the carer or person with a learning disability to verify the checks have been undertaken.



Other suggestions included: to provide pre AHC preparation information e.g. bring a fresh urine specimen and offer longer appointments for health checks:

*“need to jump through hoops with some surgeries to organise double appts and get them done this way”*

*“flexible appointment times”*

*“planned and conveniently timed appointments.”*

With a choice of location suggested by 4 respondents:

*“there should always be given the choice of having at the person’s home”*

Whilst ensuring it is:

*“completed in a relaxed environment.”*

- **Staff suitably trained and experienced**

One carer suggested that “Staff supporting people to their health check should have training in what to expect and therefore make sure it is appropriate for the person they are supporting.”. Whereas three carers suggested a pre AHC discussion with parent/primary carer before the health check should be offered.

Two respondents said the Annual Health Check:

*“should be more tailoring to suit individual needs”*

In particular where the person has:

*“complex needs ..... be more person centred”*

With

*“flexibility of approach”*

Ensuring it meets the needs of those with

*“challenging personalities”*

One respondent identified opportunities for an increased role for learning disability nurses to prepare the person before their AHC and support the GP during the AHC.

- **Independent assistance to attend the AHC**

Two respondents said there should be 'independent' assistance/support for the person with a learning disability to attend the appointment.

### **During the AHC**

- **Involvement of parent carers**

There was a suggestion that the carers (parents, etc.) of young adults should be given the right to attend with the person they care for, this was extended to the involvement of 'parent carers' regardless of the age of the person by two respondents.

- **Comprehensive/thorough**

Twenty-three comments regarding the quality of the AHC indicated that it needed to be more thorough and consistent. Respondents reported that the AHC as:

*"not fit for practice"*

Two others recommended that staff:

*"don't just go through the motions [and] actually check things"*

One carer noted that the AHC was:

*"Very basic I am not sure they would find any problems unless they were obvious"*

Whereas another respondent complained that:

*"my daughter attends she has never been given a proper health check always rushed, this one took 15 mins".*

There were three suggestions that the AHC should be:

*"more thorough;*

And, 10 suggestions that nationally it should be:

*'more consistent in content and thoroughness'*

One carer recommended:

*'local continuity.*

More checks were suggested by two respondents.

According to another carer:

*“It was a perfunctory ‘tick box’ exercise carried out by a very young and inexperienced healthcare assistant who was out of her depth with my son”.*

One respondent stated that they should:

*“Do more than just rely on the questionnaire given out beforehand”*

This was endorsed by another carer who indicated that the person carrying out the AHC:

*“Must follow the Cardiff health check<sup>12</sup> and ask all the questions, not just tick boxes guessing the answers.”*

Two respondents suggested that the AHC should be provided:

*“by people who have the ability to relate to people with a learning disability”*

And three carers pointed out:

*“Doctors and nurses should learn more about people with learning disabilities and treat them like real people.”*

While increased:

*“understanding of LD - particularly for those with more complex needs - too many ‘assumptions’ made about issues being just part of ‘condition’ [LD!]” was emphasised by one carer.*

A person with ID self-reported:

*“by understanding we have a disability though you tell them and to act on that with annual checks”.*

Practitioners must ensure they avoid making assumptions and actively avoid ‘diagnostic overshadowing’<sup>20</sup> (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities).

- **Training/experience**

Three respondents asserted that AHC’s should be provided by skilled and experienced staff with knowledge of the Mental Capacity Act.

One parent carer identified the need to consider GP training and skill mix in the health care team especially when staffing changes occur. The experience would be improved through:

*“the doctors knowing and doing whatever it is they have to do. It is not up to us as parents to tell the doctor how to do their jobs”*

AHCs were not solely provided by a doctor/GP. One carer reported that the person they support was:

*“seen by a nurse” and that they experienced ‘scant’ examination.*

Four respondents noted that where the AHC is undertaken by a Nurse\* (does not specify practice nurse for people who have a learning disability) it is essential that they are familiar with AHC.

One carer proposed that the AHC is offered as “Joint health checks involving the doctor and nurse<sup>12</sup>” but did not specify a practice nurse for people who have a learning disability.

*“We do have difficulty in the service users being examined due to their needs and how they feel about being touched. We are lucky in that the GP practise we use the GP, nurses are well informed and look at the history of the service users”*

Another respondent suggested that the person should:

*“have a choice of GP” to undertake the AHC.*

One carer pointed out that the person undertaking the checks must ‘understand’ the individual:

*“we went in with a wheelchair unable to walk at all and was told to get on to the examination table??? Needs a hoist to do this or at least two/three people to physically lift”.*

Another carer said they should:

*“carry out thorough health check on the individual out of the chair if possible”.*

While another respondent stated:

*“ensure those with complex needs also have health checks however limited”.*

- **Equipment**

There were suggestions that to achieve this the person doing the AHC must ensure they have the resources necessary to complete the health check; in particular equipment for weight measurement and a hoist for repositioning during the examination.

- **Continuity of person**

Continuity through a familiar person undertaking the health check was reported by 5 respondents. While one carer, voiced concern at the AHC saying that the person:

*“had different carers who may miss certain symptoms due to lack of continuity”.*

To carers made separate suggestions:

*“Best way is to try and have the same attendees every year”*

*“Things can always be imposed of course but I feel that after several false starts my son gets comprehensive health care support. This is helped by the fact that he sees the*

*same GP who has overseen his complex health problems for a number of years. I also have a good relationship with the GP and he is responsive to my suggestions and requests for referral for more specialist in estimations and support”.*

- **Person centred/outside the box**

Regarding the checks and tests during the appointment two respondents expressed that the health check and tests should be tailored e.g.:

*“specific to the individual” with more ‘thinking outside the box’ to achieve success with tests;*

And arrange tests to occur during the AHC appointment e.g. ‘Blood test’.

The need for an increase in focus on specific conditions was identified by one carer (Psychological), while two respondents indicated the AHC should be ‘syndrome specific’. Breast and testicular examinations were expressed as necessary for inclusion by two carers together with the need to:

*“include teaching how to self-check breasts/testicles”.*

One carer reported that he/she asked for a breast examination for the person they care for and was told:

*“she would have to make an appointment with the doctor. If the nurse is unable to carry out a full health check what’s the point!! especially when it is difficult to get her there”.*

A partner/carers reported that:

*“the nurse did discuss breast and testicle cancer but did not do an examination however I feel that it has all been left for me to examine my partner’s body”.*

Regarding ‘Healthy lifestyle information and instruction’ respondents identified the need to provide ‘sufficient time to explain things’. If the AHC “included ‘signposting’ to appropriate services would be helpful to the parent”. Support for parents was also mentioned specifically by one parent who stated “more time and consideration needs to be given to working with families”.

There was a further recommendation to “make them easy going, take out the formalities”.

## After the AHC

- **Communicating results**

After the health check, 5 respondents suggested there should be a follow-up with results and further information should be provided but to do so with sensitivity. One cautioned that those providing the results:

*“do not assume that person has always received this information”,*

And even when they have, do not assume they have understood the information.

Two respondents questioned who should receive the results and information with suggestions that the family members and/or people living together need to see the HAP (with permission) as support is often a whole family/house responsibility. One respondent expressed that the family carer should be provided with written report following AHC. Another indicated that where the HAP was developed from the AHC it needs to be kept up to date.

## **A Multi-professional approach**

A multi-professional approach is advocated by several respondents.

- Increased collaboration

One respondent asserted that:

*“The basic checks are done by staff at the GP surgery but the real depth of health action planning and assessment comes when local learning disability nurses are involved and work in collaboration with the surgery staff”.*

- **Improved information exchange**

Two suggestions were made to improve the information exchange between the primary health providers, G.P and the wider multidisciplinary team so there is confidence that AHC and HAP are completed and records updated. The individual undertaking the AHC should:

*“refer to other professionals if necessary”.*

While two respondents identified that information which has been gathered during health appointments with:

*“other health providers”*

should be a component of the AHC. One respondent specifically identified the pharmacist as a key professional to involve in the AHC.

### **Specialist role**

- **Enhanced roles**

Currently the G.P. is the main point of contact in general adult health care. Two respondents made suggestions for the development of a 'specialist' adult health role and one recounted that:

*"as a child the community paediatrician was invaluable. As an adult such an equivalent person would enhance health of disabled people greatly".*

There was concern about the generalist nature of the role of the G.P. with one carer indicating that the AHC requires:

*"a whole person approach - gp's - ... - they just don't have the knowledge for someone with very complex needs".*

And two respondents said:

*"specialist team should do this who understand disability"*

One respondent suggested that the check should include an "expert by experience"<sup>21</sup>. There is an opportunity for a health advocate role to support individuals where they are requested or the need is established through 'best interests'.

The AHC could be improved if how to support the partner of the person attending the AHC is considered. At what point does the person undertaking the AHC consider the dynamics of their relationship and their support needs? One partner/carers expressed:

*"I feel that it has all been left for me to examine my partner's body. This is not my job and I am not qualified to do it".*

Two respondents suggested that the enhanced service fee is removed:

*"don't think the surgery should expect to be paid an enhancement for caring for vulnerable community members";*

*"this scheme should be a standard part of the role of the GP not optional"*

Satisfied respondents noted:

*"I am quite satisfied in how it is carried out by the practise nurse"*

*"Our practice I would regard as excellent....The only improvement I would say that everyone should have the same level of service we are afforded".*

Fifteen respondents did not make suggestions for improvement.

It is apparent from the responses that there is a need for consistent terminology to identify the population of focus, the terms “Learning Disability”, “Learning Difficulty” and “Special Needs” and “Intellectual Disability” are all used. Furthermore, the terms Health Action Plan (HAP) and Annual Health Check (AHC) are being interchanged, some respondents think they are the same while others refer to both. However, as far as authors in academic journals are concerned the term “Intellectual Disability” appears to be used internationally and “Learning Disability” is mainly used in the UK.

#### 7.2.4 Respondents feelings about extending the AHC to young people aged 14-17y

Q31: The Annual Health Checks are to be extended to young people aged 14-17<sup>19</sup> to support transition to adulthood and to introduce health action planning. How do you feel about this?

These changes were due to happen in April 2014

184 respondents

Good idea = 176

Ambivalent to the idea = 2

N/A or ‘No comment’ = 6

**Figure 7.2.4 Diagram to show respondents’ feelings about extending the AHC to young people aged 14-17y**

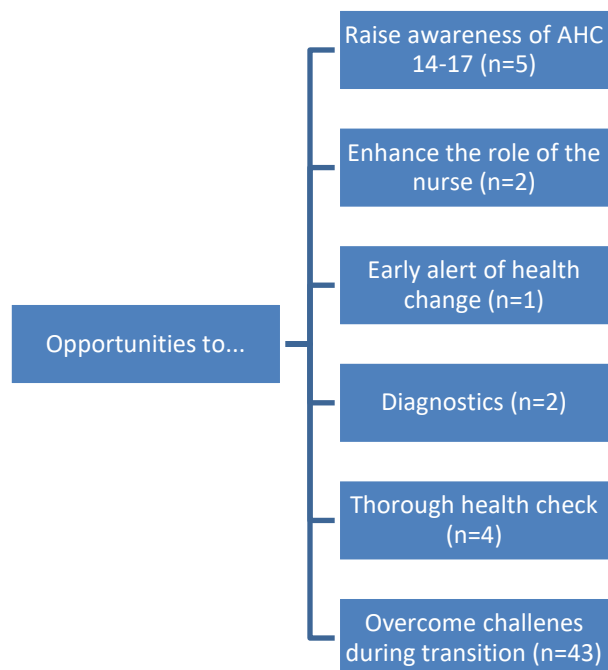


Figure 17.2.4: Diagram to show respondents’ feelings about extending the AHC to young people aged 14-17yr



Of the 184 respondents in support of extending AHCs to young people aged 14-17, responses indicated hopes and aspirations as well as healthy scepticism acknowledging current limitations in services. R75 stated that AHCs are “essential to improving the health needs and identifying ill health”.

- **Opportunities to raise awareness of AHC**

Five respondents suggested opportunities to raise awareness of AHCs. R159 stated:

*“Excellent, if the people being offered the health check are well supported to understand what and why this happens.”*

One respondent emphasised that parents/carers need to be aware of the checks being offered:

*“that is a very good idea but only if gp surgery’s actually let parent/ carers know about them”.*

- **Enhance role of nurses**

Two respondents mentioned the role of the nurse in their responses. One said that it:

*“Sounds an excellent idea especially as the role of community nurse is being rationed and time-limited”*

Although another was more cynical identifying extended AHCs as:

*“waste of time, GPs only doing it for the money and our surgery gets a nurse to do it”.*

Both respondents presented opportunities to develop the role of the nurse during AHCs.

- **Early alert of health check**

A respondent thought these extended health checks would give opportunities to improve the health of the young person with the AHC providing an early alert to anticipate health change.

- **Diagnostics**

Two respondents suggested that there would be diagnostic opportunities for identifying Learning Disability.

- **Thorough health check**

Four people felt that the AHCs gave opportunities for a thorough health check for young people.

- **Overcome challenging during transition**

Eleven respondents anticipated that during implementation numerous challenges and opportunities would be encountered.

One respondent noted:

*"That would be good so long as people know about them especially GPs"*

And another said:

*"a good idea as GPs often don't know the young person who would have been seen only by paediatrician at "hospital". Yet another also said:*

*"Sounds good as long as someone supports that action plan otherwise it is just a paper exercise"*

One respondent commented:

*"Can only be a good thing but the GP capacity is limited"* Thirty-two respondents made suggestions for opportunities to improve the transition period between childhood and adulthood in relation to health checking and support provision.

A positive comment was made by one carer:

*"I think that this is an excellent idea and will vastly improve the transition from Children to adult services"*

But another said:

*"It depends how sensitively the surgeries are prepared to be when they offer health checks to teenagers... and if they are prepared to take no for an answer."*

However pragmatically it is asked where the responsibility will lie to commission and coordinate this service respondent asked:

*"Good but who's responsibility CLDT and PCLN commissioned from age 18 not 14". (CLDT: Community Learning Disability Team; PCLN: psychiatric consultation liaison nurse)*

And:

*"good idea but who will coordinate that. adult services?? local children's services wont"*

One respondent asserted:

*"I think it should be the same core team from the cradle to the grave."*

Whilst another pronounced:

*"All progressive moves are fantastic, and should be encouraged. Eventually the practice will embed".*

Twenty-one respondents, through sceptical responses, acknowledged the reality of experiences during the implementation of adult AHCs and the increased demands on what is reported as being a stretched service. Examples include: *"Fantastic...but GPs are failing with adults so I have no confidence they will cope with expanding this to include children!"*

*“Not happening in adult so possible not take place in children”;*

*“It sounds like a good idea but will they also be ignored? If surgeries don't conduct the over 18-year-old ones what chance do the other age groups stand?”*

And expressions of:

*“Low confidence that GPs will take it seriously as they have other priorities and number of LD patients not significant.”*

Questions about the rigor of the new EHC Plan<sup>22</sup> were brought into question, for instance: *“Should this not already be in place with EHCP?” “It is a good idea but let's face it, the transition from childhood to adulthood within the normal schooling process does not happen, it also does not happen very often with social services either, so how is it going to work within the health service, sure all these ‘Professionals’ should meet at least annually to discuss their patient” “I imagine it will be another paper exercise with little specific benefit to LD people, More work for over stretched GP practices.”*

*“This is a good idea but is there capacity in the system to ensure this happens?”*

*“A Good idea in principle, but will it stretch the services of GP practice.”*

*“Good idea but GPs are not compelled to do these checks. They have to sign up to the enhanced scheme.”*

The quality of the AHC is also pertinent to respondents. Introduction of the AHC from 14 years upwards is:

*“Good if the checks are good otherwise wasting everyone's time and the GP claims money for poor service”*

And:

*“This is a good thing as long as they are done properly”*

### 7.2.5 Respondents opinions about the person with ID being given a Health Action Plan (HAP) when they have their AHC

Q32: What is your opinion about the person with learning disabilities being given a Health Action Plan when they have had their Annual Health Check?

192 respondents

Supportive = 148

Suggestion to enhance = 40

Ambivalent = 14

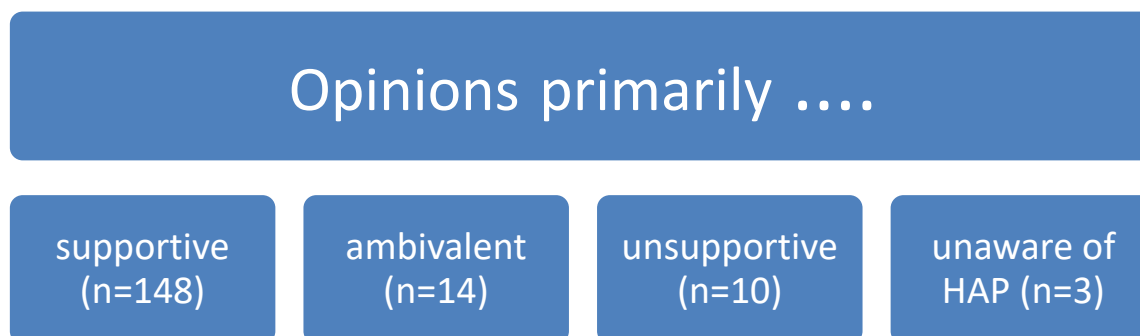
Unsupportive = 10

Unaware of HAP = 3

Not applicable = 11

No comment = 6

**Figure 7.2.5 Diagram to show themes in respondent opinions about the person with intellectual disabilities being given a Health Action Plan when they have had their Annual Health Check**



**Figure 18:** Diagram to show themes in respondent opinions about the person with intellectual disabilities being given a Health Action Plan when they have had their Annual Health Check

- **Supportive**

Respondents who were supportive of the provision of a Health Action Plan when they have had their Annual Health Check indicated that it was a:

*“A good idea as it is useful to have a written plan as it is hard to remember and health goals to work towards. Having checks annually help keep track of a person’s health and any problems hopefully can be spotted early and treated.”*

*“It gives a clear physical reminder of what was agreed in the Health Check, acts as a record of when the health check was carried out and may provide an incentive to keep to a healthier lifestyle.”*

*“It’s essential to plot and discuss outcomes and future actions even if it’s just a repeat assessment in 12 months”*

Respondents provided suggestions and tips to identify how this could be achieved. Suggestions included ‘easy read and pictorial examples’; ensuring legible handwriting in hand written HAPs; and that successful communication established between all parties developing the HAP. A further focus was on preparing individuals and carers to understand what the HAP entails and easy understanding and familiarity through a national ‘consistent format’ for the HAP e.g.:

*“Great & even better if same format used for everyone...better for carers to work with if all the same format!!*

Following the HAP three carers suggested that it should be “need to know” document and should be shared with all parties supporting the individual and two suggested that carers need to be trained/supported in delivering the ‘actions’ within the HAP.

One carer suggested that there should be the provision of follow-up appointments to ensure clarity and understanding.

Another carer commented about who completes the HAP with the individual:

*“my daughters was completed by an LD nurse after several home visits when she came under the care of adult services. Better to use an LD professional rather than a practice nurse.”*

- **Ambivalent**

Three respondents who were ambivalent indicated that the HAP was “superficial”; “over kill”; and “common sense” e.g.

*“These are completed by other professionals in our area, pointless to duplicate and confusing for some.”*

There was concern about the increased effort by the carer:

*“the Carer has to update and this can be a burden keeping it up to date and monitoring it for all concerned”*

While one respondent was concerned that the AHC might raise the anxieties of the individual.

There is a marked difference between the role and responsibilities of the paid carer with those of the family carer and these would be worth exploring as part of the implementation for offering HAPs. Clearly, those parents who have responded have a clear understanding of the health needs and required actions for their son/daughter. The key action of importance is that this is clearly communicated to those who have a paid responsibility to care for the person who has a learning disability which complements the parents' role.

- **Unsupportive**

Responses against this implementation were highly emotive, where carers reported the provision of the HAP would be a:

*“pointless waste of time”*

*“patronising and time wasting, more duplication”*

*“I would feel patronised if it were only about exercise and food... we've done a good job so far!”*

*“I don't need a plan for my child I need him and me to be listened to when I raise concerns, if you have a person centred plan all should be on that.”*

*“Most families will have this in place in their own way as they would for any sibling, if specialist support needed it should be available, if families are unable to do this or there are concerns about the individual then that should be part of the support.”*

One respondent expressed the need to get to know the person across the year rather than one 'review and plan':

*“I do not like the idea of LD people being given a 'Plan' They like everyone else are entitled to make their own choices. I would prefer more time spent talking and getting to know them/advising them over the year rather than In/Out -Tick boxes -Next please!”*

- **Unaware of HAPs**

One respondent expressed grave concerns about the implementation of the HAP although they indicate the person they support did not receive one:

*“if we had been it would have been worthless, and I have a much better insight into his care than this service does. I'm not sure I'll bother taking him again”.*

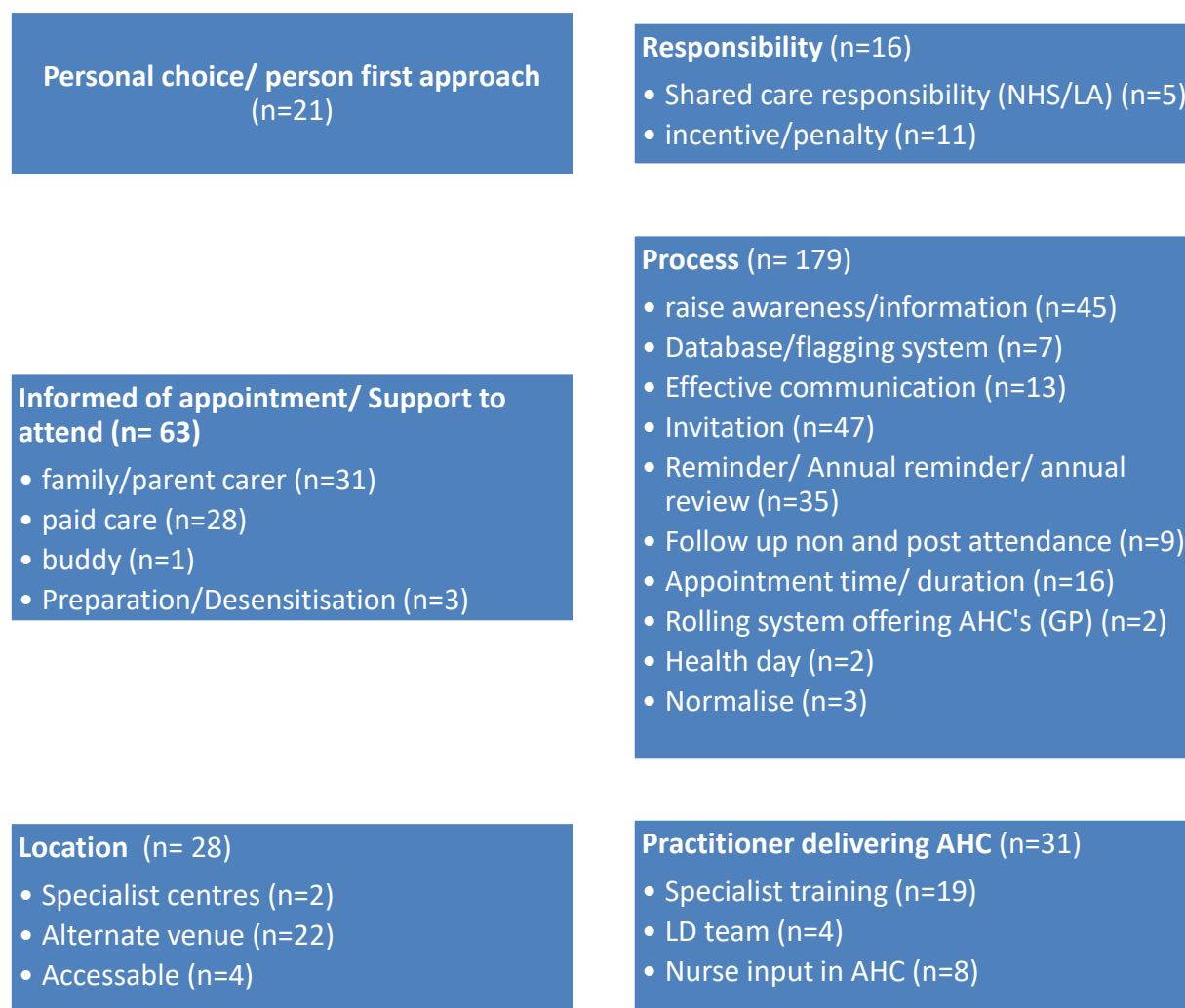
This is of greatest concern; the implications of one poor experience may lead to disengagement with vital health services which will extend throughout the individual life until such time as the parent/carers selects to reengage.

## 7.2.6 Respondents opinions about the best way to make sure people with ID go for AHCs

Q33: What do you think the best way would be to make sure more people with learning disabilities go for the Annual Health Checks?

193 respondents

**Figure 7.2.6 Diagram to show themes in respondent opinions about the best way to make sure people with ID go for Annual Health Checks**



*Figure 19 Diagram to show themes in respondent opinions about the best way to make sure people with ID go for Annual Health Checks*

Respondents recommendations included: the improvement within the AHC, raising awareness at all levels, ensuring individuals have information to assist in making an informed decision, with suggestions for improving the experience [similar responses to Q30] rather than addressing how to 'make sure people go for an AHC'.

- **Personal choice/person first approach**

Some respondents questioned whether the focus should be on 'making sure people go for an AHC' indicating it is preferable that the person with a learning disability decides whether to take up the offer of the AHC.

Eight respondents indicated that it should not be enforced but should be the decision of the individual and two respondents suggested that where they lack capacity to decide that this should be a 'best interest' decision and to involve the family/paid carers.

- **Responsibility**

Suggestions to encourage attendance included:

*"Make it informal and give an incentive."*

*"relevant incentives for person with LD to attend (Gift voucher, cinema ticket, etc.)"*

*"Incentives for the person and carers"*

One particular point of note was the suggestion to make them more fun and a comprehensive activity "make it a bit more fun too. It could be a day long health session, with a chat about health, examples of healthy lunches etc., and some exercise in the afternoon. "You can't just talk to our young people sometimes you need to show them."

Compulsory attendance was also suggested:

*"make it compulsory just like attending school"*

One person suggested that there should be increased responsibility to ensure AHCs are offered and another stated:

*"Make it compulsory for GPs to offer this check-up and publicise with paid and unpaid carers".*

The application of penalties for non-provision were also proposed by another respondent.

There were suggestions that penalties should be imposed where carers do not support the person to attend. It is unclear whether this is seen as solely the responsibility of the 'formal paid' carer or whether there is the expectation that this extends to the 'informal unpaid' carer. Regardless of who is deemed responsible there remains a 'duty of care' and where the individual is 'at risk' safeguarding concerns need to be raised:

*"Ensure that their support provider if non family take them to appointments if they consent, if a best interest decision is needed then do it and record it to ensure that all opportunity is explored to access health services."*



- **Process**

There was particular focus on the flexibility of appointments by two people and the venue where the AHC takes place. Appointment times were said to need to accommodate the daily demands of the individual and their care team:

“at a time suitable to them [person who has a learning disability].”

*“the carer needs to be informed of the date and time”*

*“Not to have to queue for some time, and a strict appointment be given.”*

*“Our health check was initially offered at a time of day unsuited to my daughter's needs so the surgery kindly adapted to another time. Both of these were within the hours covered by her care package. I can imagine problems if appointments are offered outside the time range of the care package.”*

- **Location**

In addition to the Health Centre, a variety of venues were suggested as potential locations to offer the AHC, including: at home by three respondents; another three-people suggested day support; school was suggested by two people and college and workplace by one respondent.

“at their day centre if they attend, if they are like my daughter staying away from the day centre is not acceptable.”; “maybe health professionals going to the persons’ home.”; Two respondents advised that the AHC should be offered in specialist clinics.

- **Informed of appointment/support to attend**

A variety of professionals were identified as necessary to improve the engagement. Specialist training was identified for all involved, including a suggestion for a G.P. with a senior practice nurse, three suggestions for a health visitor and one for a Learning Disability Nurse. A Learning Disability Practice Nurse was suggested by three respondents, while two suggested Learning Disability Team members and specialist Doctor. There were two suggestions for the development of a Learning Disability champions in Health centres/GP practices or one suggestion to train the carer to undertake the AHC.

Is this a call to return to the Responsible Medical Officer role?

### 7.2.7 Respondents other comments about AHCs

Q34: Any other comments about the Annual Health Checks?

109 respondents

Supportive comments = 51

Increase awareness of AHC = 13

Opt out (person they support) = 2 (unclear who's decision to opt out)

No further comments = 11

**Figure 7.2.7 Diagram to show themes in respondents' other comments about Annual Health Checks**

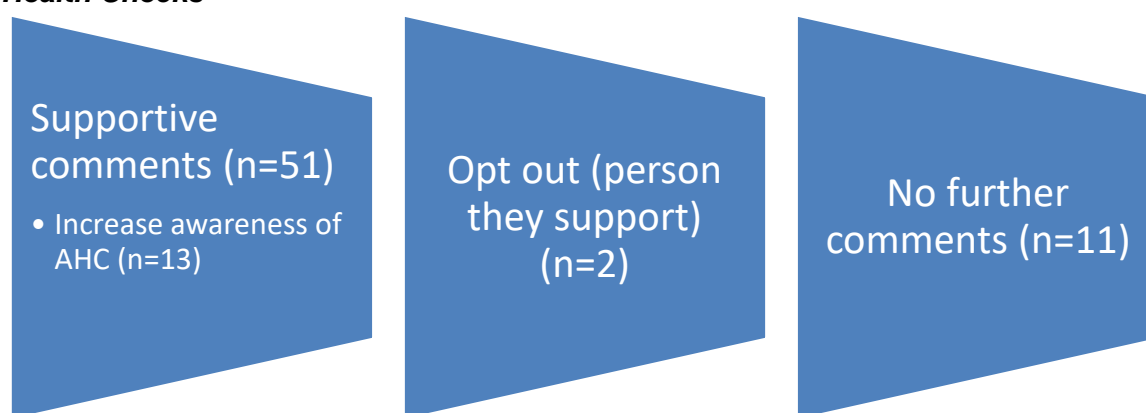


Figure 20 Diagram to show themes in respondents' other comments about Annual Health Checks

This 'catch all' question at the end provided the final opportunity for respondents to comment about the AHC. For most respondents it was an emotive, supportive, expression that focussed on the frustration from AHCs which were less than satisfactory. It was also an expression of dissatisfaction, a plea for improvements and for recognition or a statement of opting out of the offer of an AHC. *"People should be made accountable should they not provide this to individuals - unless the individual opts out"*

A sobering final comment by a respondent:

*"I think that if there is no response to an annual health check call up for a person and that person has not been seen in a year that a check should be made that everything is ok with that person (with a view to possibilities of abuse that may come to light as a result). and if necessary that check should be made by a social worker or even the police (yes I would go so far as that especially in view of the man who had been kept a prisoner in a garden shed for years while a family had cashed his money)."*

## 8 Discussion

The majority of people with ID in this study have been shown to be male (63% male to 37% female) as with other studies<sup>2 4 8 11 16 23</sup>. Some other studies show that the proportion is 3:1<sup>24</sup>.

The reason for this ratio may be because of referral bias<sup>23</sup>, males with ID are more likely to be referred because of their behaviour for example hyperactivity<sup>23 24</sup> rather than females, among whom the numbers with ID may be similar but undiagnosed<sup>24</sup>. Moreover, this could be because of the higher proportion of males to females having autism spectrum disorder (ASD)<sup>25-27</sup>. Fombonne *et al.* reviewed 14 studies and found that there was a range of 30%-85.3% of people with autism may have an intellectual disability with a mean of 56.1% without ID<sup>28</sup>. Difficulty with reading, which is a symptom of ID, was found to be similar between genders which indicates that many females may be undiagnosed<sup>29</sup>.

As this survey was mainly distributed electronically with only a few paper copies being distributed it means there was self-selection bias operating in the carer population. People who had access to the internet and were familiar with social networks were more likely to take part. As a slight majority of carers were members of blogs and many were members of carers' organizations this also may be unrepresentative of the general carer population and may have given these carers more of an insight about people with ID and AHCs.

The percentage levels of ID of 13.1% mild; 30.0% moderate; 41.3% severe; and 15.5% profound, did not agree with those found in other studies. Cooper *et al.* (2006)<sup>2</sup> found 38.9% had mild, 24.2% had moderate, 18.9% had severe and 18.0% had profound ID. Moreover, the CIPOLD study<sup>4</sup> showed 40% to have mild, 31% moderate, 21% severe, and 8% to have profound and multiple ID. The levels were determined using criteria defined in a personal communication<sup>30</sup> however, BILD (British Institute for people with Learning Disabilities) uses different criteria<sup>31</sup> hence assessment is difficult. The people taking part in the present survey were self-selected leading to selection bias hence this may indicate a lack of representation of the population. Of the 233 aged 18 or over taking part in the CIPOLD study most (92%) were identified as being on a GP register of people with intellectual disabilities<sup>4</sup>.

The percentage of people with ID not having an AHC was 45.4% (No AHC/ NA/ Other), which is close to that found by English Strategic Health Authorities (48%)<sup>8</sup>. However, a much lower figure was found by the CIPOLD study where 29% of people with ID did not receive an AHC in the year before their death and 12% had never had an AHC<sup>4</sup>. This lack of agreement in the CIPOLD study may have been due to the high number of people living in residential care homes (64%)<sup>4</sup> so a higher referral rate to the GP may have taken place. The AHC is one way to prevent premature deaths in people with ID. However, in line with other reports<sup>11</sup> a high percentage of people with ID did not attend an AHC. This could be attributable to 52.7% not receiving an appointment letter from the GP and also 62.6% not receiving an appointment reminder. From the perspective of the person with ID again the

majority did not receive an easy-read letter. Carers' opinions about "easy read" (Figure 7.5) may influence whether the person with ID has access to the easy read letter or not.

The present study shows that people with ID were more likely to have an AHC if cared for by a paid carer (Table 7.1) rather than by family which is a similar finding to that of McConkey *et al.* (2015)<sup>18</sup> but in the present study the percentage being cared for by paid carers was comparatively low. As with the present study where 83% of the people with ID were in the care of the family or friends, IHAL<sup>8</sup> reported the highest percentage of people with ID as living with family or friends in England in 2010/2011 (29%) followed by residential care homes (16.9%) supported group homes (12.7%), tenancy (12.5%), adult placement (1.9%), shared ownership housing (1.7%), nursing homes (0.9%), acute/long stay/hospital (0.8%) and sheltered housing (0.5%)<sup>8</sup>. This lower number of people in residential care homes may explain the closer agreement of the attendance at AHCs with the present study. That families are less likely to take the person with ID for AHCs than paid carers (Table 7.1) suggests that there needs to be more promotion of AHCs to family members. The percentage of GPs which take part of the AHC scheme varies across the country<sup>11</sup>

Figure 2 in Public Health England "The Uptake of Learning Disability Health Checks 2013 to 2014" showing the coverage of learning disability health checks for NHS England area teams, demonstrates that apart from incomplete data, uptake varies from 29% to 62.2%<sup>11</sup>. McConkey *et al.* (2015) found that areas in Northern Ireland which employed health facilitators increased uptake by GPs of the AHC scheme<sup>18</sup>. Health facilitators have also been used in England and Wales<sup>32</sup> and is something that needs to be considered further by strategic health authorities. It was found that more blood tests and other measurements and assessments were done in GP practices under DES than in non-incentivized practices<sup>17</sup>.

The qualitative analysis showed that there were several reasons given by GPs to carers for not offering AHCs such as people with Asperger's syndrome not qualifying even when it was stated the person had ID and another reason given was lack of GP funds. Assumptions were also made by carers about the AHC not being offered or needed, for example, opportunistic health checks happening, or hospital attendance making AHCs unnecessary. Carers also showed frustration at the lack of AHCs being offered for instance by proxy with the carer over the phone or being promised an AHC but no follow up. Some carers pre-empt an appointment by booking a health check for their charge and others feeling that the onus is on the carer to make sure it happens. There were also reasons given by carers for non-attendance of the AHC even when offered. These ranged from challenging behaviour by the person with ID to the carer's health and or disability, lack of support and travelling distance. Some carers claimed their charges were healthy enough not to need an AHC. Lack of awareness by carers of the AHC and also confusion between AHCs and HAPs affected attendance. Cancelled and confusion over appointments was also given for lack of attendance. Some carers felt that the AHC should be carried out somewhere other than the GPs at home for instance. The majority of carers supported the HAP and made suggestions to improve it. However, there was also some ambivalence and lack of support; some carers feeling it was a waste of time, liable to duplication and only short term.

For these reasons services need to provide person-centred support so that carers feel supported to attend and that environments are safe. Adequate preparation should be provided to desensitise the person so they are prepared for and are comfortable with the health checks, but more importantly a transformation needs to happen that transfers from reactive responses to health change and health decline to a proactive approach with health checking and health protection and promotion approaches.

This all emphasises the need for a campaign to ensure GPs provide AHCs when signed up to DES and carers to know of the availability of the AHC and to be supported to make sure people with ID attend the AHC; unless the individual with ID makes an informed decision and chooses not to attend the AHC.

CIPOLD<sup>4</sup> named the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in people with intellectual disabilities. Only a few (23%) cause of death certificates mentioned that a person had intellectual disabilities. Fewer deaths of people with intellectual disabilities (38%) were reported to the coroner compared with the general population (46%). When deaths were reported to the coroner, people with intellectual disabilities were more likely to have a post-mortem and were as likely to have an inquest opened. Of note is that the CIPOLD Overview Panel identified some additional deaths that the panel thought should have been reported to the coroner, and expressed concerns about some coroners' reviews of deaths<sup>4</sup>.

In the CIPOLD<sup>4</sup> study, a death was considered as premature if, "without a specific event that formed part of the "pathway" that led to death, it was probable that the person would have continued to live for at least one more year". This allowed the Overview Panel to take account of both lifestyle and co-morbidity in assessing the potential significance of events or omissions in the care of the person concerned, regardless of their age. Of the 238 deaths of people with intellectual disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs. Hosking *et al* 2016<sup>6</sup> found that the third of deaths among people with ID that were amenable to health care were specifically seizures, respiratory infections and urinary tract infections and that lifestyle behaviour lead to some of them.

This issue was illustrated by the qualitative analysis where one respondent alleged that paid care staff had not acted on three invitations for the AHC for his/her brother resulting in him being removed from the GP register. The outcome was fatal for his/her brother and the alleged implication was that this would not show up as an uncompleted AHC making the GP's statistics appear better.

The content of the AHC was very variable (Table 7.5). Tests which are easy to do and which would indicate a wide range of illnesses such as weight, height and blood pressure measurements were the most common. Questions such as whether the person smokes or takes alcohol were also commonly asked possibly for similar reasons. Despite guidance from the RCGP 2010<sup>12</sup>, examinations such as those of breasts and testicles were rarely offered or carried out but as cancers of these tissues are serious but curable if discovered early, it could be argued that these should be included routinely in the AHC. Comments from respondents also advocated breast and testicle examinations with perhaps teaching the individual how to self-examine. One carer was told to make a separate appointment for a breast examination for their charge and another felt that as the examination was only discussed with him/her and that it was up to him/her to examine his/her partner. Some carers advocated tests tailored to the person with ID; more specific to their needs. In the light of this information an audit tool exists to help GPs decide whether they are carrying out the AHC satisfactorily to meet all aspects of the person with ID's welfare<sup>33</sup>.

All aspects of carer satisfaction with the AHC were unaffected by whether a doctor or nurse carried out the AHC (Tables 7.6 and 7.7). This would indicate that the cost of the AHC could be cut and efficiency improved by the increased use of nurses whether to free up the doctors' time or to cut salary costs without affecting patient satisfaction. The local learning disability nurse's involvement was advocated by one carer who felt that it gave better in-depth HAP and assessment. Whereas other carers suggested more information exchange between GPs and the multi-disciplinary team including the pharmacist for more thorough AHC, HAP and record keeping.

However, carer knowledge of the number of tests which could have been done compared with those actually done significantly reduced carer satisfaction which went down with fewer tests done (Table 7.8; Figures 7.6 to 7.13) indicating that the number of tests affected the way patients feel about the thoroughness of the AHC. Some carers suggested that the health check and tests should be tailored to the individual. However, standardization of the AHC was recommended by CIPOLD<sup>4</sup>. Besides the present study, variability was also found in the content, quality and recording of AHCs in the CIPOLD reviews and so it was recommended that minimum requirements for AHCs are introduced, with the updated Cardiff Health Check as the standard template for AHCs in people with ID for national use. CIPOLD recommended that the AHC be done by an experienced fully-trained doctor who should provide the person with a Health Action Plan which clearly identifies the health issues, the person who is responsible for addressing these issues and a specific timeframe in which they will be achieved<sup>4</sup>.

Some carers felt that the AHC should be compulsory within the GP contract rather than under the incentivized scheme. Some felt penalties should be given for non-provision of the AHC and also for carers who did not support the individual to attend. Flexible appointments were also felt to be needed in time and place. Many respondents commented that the AHC should be standardized and available to all people with ID. The extension of the AHC to people aged 14-17 years old was supported by most carers although there was some

scepticism and lack of confidence expressed. Carers felt that it would for instance, raise awareness, give an early alert of health change, diagnostic opportunities and overcome challenges during transition.

Respondents gave differing opinions on the best way to ensure people attend AHCs. Some felt that people with ID should decide themselves whereas others felt it should be compulsory. These opinions were probably given in the light of the severity of the ID so that those individuals with mild ID might be able to make their own decision. However, some carers felt it should be a “best interest” decision and involve family carers. Incentives to attend seemed popular. There was also a suggestion that the carers (parents, etc.) of young adults and also of older adults should be given the right to attend with the person they care for. Overall the feeling was to increase engagement by good training or all professionals involved.

## **9 Conclusion and recommendations**

### **9.1 Conclusion**

Twice as many males as females were found to be ID although selection bias may have influenced this result. All results may have been influenced by other sources of bias.

Percentage levels of ID were 13.1% mild, 30% moderate, 41.3% severe and 15.5% profound. These percentages did not agree with other studies due to differences in criteria and bias.

45.5% of the surveyed carers (or ID people) said the people with ID they cared for did not have an AHC which, in line with other studies, was lower than the AHCs available (85% of GPs). This figure was contributed to by 52.7% not receiving a GP appointment letter and 62% not receiving an appointment reminder.

People with ID were more likely to have an AHC if cared for by a paid carer rather than by family. Although 83% of those surveyed were cared for by family.

Several reasons were given by GPs to carers for not offering AHCs e.g. the person having Asperger’s syndrome even if the person had ID and lack of funds were amongst the reasons given. This often caused frustration to the carers.

Carers also gave reasons for non-attendance of the AHC even when offered, including challenging behaviour by the person with ID, carer’s health, lack of support, travelling distance and the health of the person with ID being good enough not to need an AHC. Attendance was also affected by confusion over AHCs and HAPs and also cancelled and confusion about appointments. Some carers felt that AHCs should be done in places other than GPs. There was also a suggestion that the carers (parents, etc.) should be given the right to attend with the person they care for.

The content of the AHC was found to be very variable; straightforward tests such as those for weight, height and BP and which indicated a wide range of illnesses were most common.

For similar reasons questions, such as whether the person smokes or drinks alcohol were the most asked.

Importantly, examinations of testicles and breasts were rarely done despite the serious diseases that may be discovered.

Carer satisfaction with the AHC was unaffected by whether a doctor or nurse did it but the level of satisfaction reduced with the fewer tests done indicating dissatisfaction with the thoroughness of the AHC.

Carers felt that a standardised AHC should be offered within the GP contract as a compulsory component and penalties should be given for non-provision. Carers also felt the extension to ID people from 14 to 17 years old was a good thing but also expressed scepticism.

Opinions about best way to ensure that ID people go for AHCs varied from ID people deciding for themselves to AHCs being compulsory. Best interest decisions were recommended involving families, incentives and increasing engagement by increasing training for professionals.

## **9.2 Recommendations**

- The number of people with ID attending and invited for an AHC needs to be increased. This may be done by increased training, awareness, advertising, correspondence and coordination of and between healthcare professionals, carer organisations and social services etc.
- Incorporation of the AHC into the GP contract should be considered so that all people with ID are made aware of its availability.
- Standardisation of the AHC is necessary to ensure that the same content is offered to all. This may be taken from “A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability, 2010.”<sup>12</sup> or a similar regime.
- Tests which reveal serious diseases should be considered for inclusion in the AHC such as breast and testicle examinations.
- An appropriately trained and experienced nurse can be used to carry out the AHC without detriment to standards which may “free up” the doctor for other tasks and to cut costs.
- Services need to provide person-centred support so that carers feel supported to attend and that environments are safe.
- Consideration should be given for carers (parents, etc.) of young adults and also of older adults to be given the right to attend with the person they care for.
- Adequate preparation should be provided to desensitise the person so they are prepared and relaxed with the health checks.
- A transformation from reactive responses to health change and health decline to a proactive approach with health checking and health protection and promotion needs to happen.



- A standardized term for learning disability is recommended for use, possibly this should be the term “intellectual disability” which is the term most used internationally. Also, the AHC and HAP have become used interchangeably and these terms need clarifying.

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## **11 ANNEX**

Qualitative Analysis Questions 7 – 17 and 21, 25 - 26

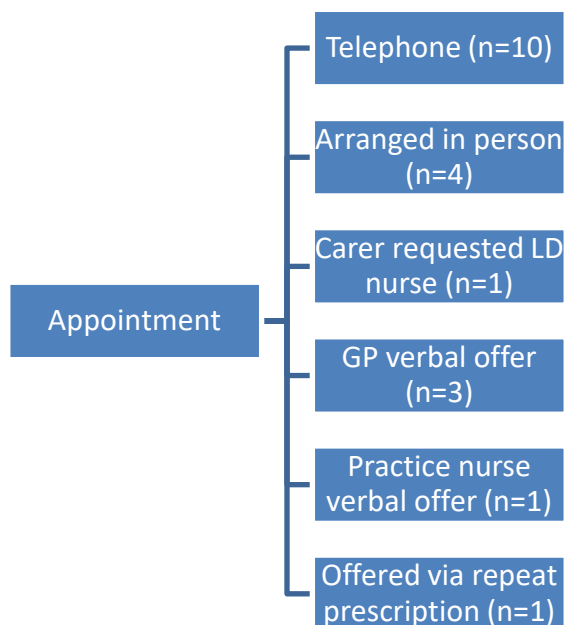
### **Analysis of open questions**

Responses to individual questions identified below:

### 11.1 Q7. Did you receive an appointment letter for the AHC? Other, please specify comment

26 respondents

Null = 6



Annex Figure a: 11.1, Q7. Did you receive an appointment letter for the AHC? Other, please specify comment

In addition to the appointment letter a variety of approaches were identified, including contact by telephone n=10; respondent, family member or paid carer arranging appointment in person n=3; GP suggestion during appointment n=3.

Other approaches included carer asking for an appointment, respondent R107 stated they

*“asked for learning disability nurse health team to come out”.*

While R189 indicated [I],

*“was told verbally by the GP practice nurse”*

whilst R179 stated that the

*“Surgery made appointment when I ordered drugs”.*

Obtaining an appointment was not always straightforward; R200 expressed

*“I had to ask for appointment. GP not forthcoming with appointment and thought not necessary. I had to push for it”*

**11.2 Q8. Did your letter come with an easy read version? Other, please specify comment**

**16 respondents**

Seven respondents were unsure whether they received an easy read version. There may be several reasons for this uncertainty, they may be unfamiliar with what an 'easy read' document may look like or they did not receive an easy read version. R278 was unsure stating that "*Mum deals with health*", while R204 identified "*my daughter is still at school and the health check is still completed by the paediatrician in school.*"

Five respondents indicated they did not receive a letter (these are more appropriate as responses to Q7).

### 11.3 Q9. What do you think of "Easy Read"?

#### 18 respondents

(4 stated 'Not Applicable' in their response.)

Four had not seen easy read information so unable to comment, while R188 gave support stating that

*"I haven't seen it but it is a good idea."*

One respondent said

*"no good to me as I can read, don't mind easy read versions but hate reading them when it's me doing the reading" (R198).*

This presents a potential challenge to services deciding which format to send and to whom.

One carer states Easy Read is "Not appropriate for my son due to level of ability" (R11). Suggestions included the opportunity to "Opt in for [easy read] version" (R45) and for the sender to "Just write the original letter clearly (R166).

Additionally, in responses to Q32 respondents gave comments about the value of easy read and it being provided in advance of appointments so that the person has time to understand the information. Concern was indicated about the ability of the person understanding and acting on the information independently with suggestions that 'Easy read' should be supported by information for the carer.

*"send them the letter in easy read and a normal one for the carer" (R111);*

*"Excellent idea as long it's in easy read and it is also copied to the rest of their support team" (R124)*

*"This is a good idea if it is in an easy to read format and there is support for the person with learning disabilities to implement it." (R251).*

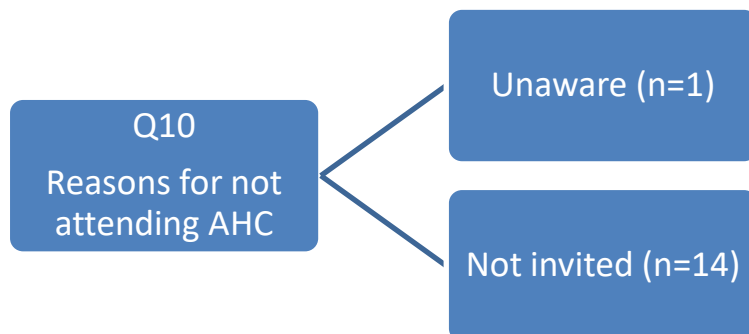
## 11.4 Q10. Does the person you care for go for the Annual Health Checks?

### 36 respondents

Never invited = 14

Unaware = 1

Null = 21



Annex Figure b: 11.2, Q10. Does the person you care for go for the Annual Health Checks?

One carer indicated that he or she was unaware of Annual Health Checks (R7). However, there is uncertainty in responses with some respondents demonstrating lack of distinction between Annual Health Checks (AHCs) and Health Action Plan (HAPs).

14 carers indicated that the person they cared for had not been invited for an Annual Health Check, comments include;

*"I would like her to, but have not been invited", (R123);*

*"no she has NEVER been invited" (R10);*

Some individuals identify arranging the appointments of behalf of the person with a intellectual disability, not waiting for invitation.

R77 indicated

*"down to Carer to remind GP who never follows up";*

*"not able to get an AHC I book a double apt" (R120).*

*"she has in the past - if I organise but haven't had 'annual' checks. Currently is it over 12 months since the last one I arranged ..." (R144).*

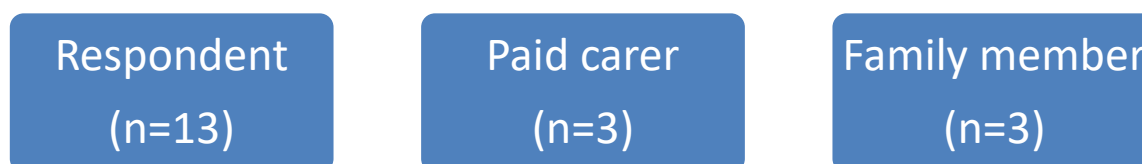
Health checked annually include, asthma review (R213), blood tests (R188), flu jab (R188) and medication review (R113) undertaken but not clear if opportunistic health checks took place at the same time.



**11.5 Q11. If "Yes" who takes the person to the appointment? Other, please specify comment**

**19 respondents**

1 null return



*Annex Figure c: 11.5, Q11. If "Yes" who takes the person to the appointment? Other, please specify comment*

Thirteen respondents reported they accompanied the person to the appointment. R228 stating, "I support but he speaks for himself and I expect the GP to talk to him" whereas R194 indicates due to council cuts in care they support their son to attend the appointment "*I do. Son live 'independently'.*"

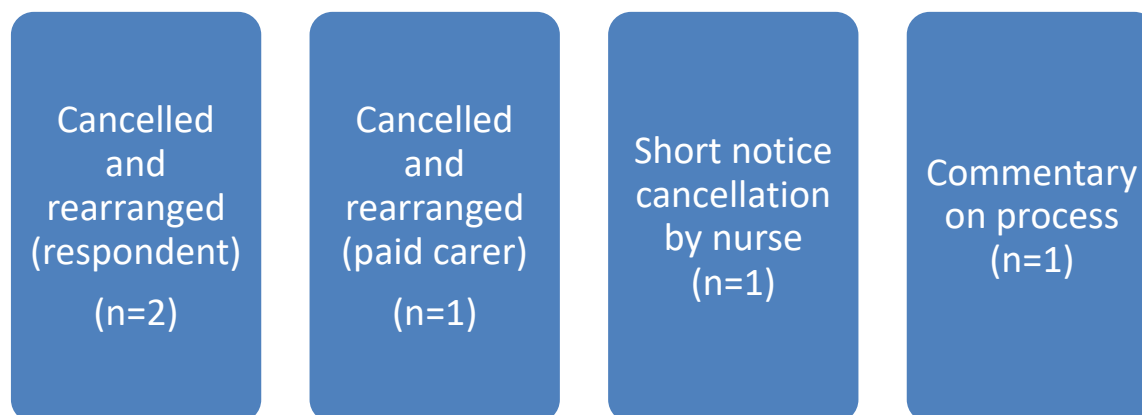
Respondents 36, 46 and 248 identified that they usually accompany a paid carer. R270, stated that the residential carer supported the individual to attend the appointment. Three individuals indicated that a member of the family other than themselves would support the person to attend the appointment.

One person (R7) stated that they had not heard of health checks before.

**11.6 Q12. If "Yes" but you weren't able to take the person on the day of the appointment did you cancel it and make a new appointment? Other, please specify**

**7 respondents**

2 null returns



*Annex Figure d: 11.6, Q12. If "Yes" but you weren't able to take the person on the day of the appointment did you cancel it and make a new appointment? Other, please specify*

R131 and R231 identified they had cancelled and rearranged the appointment. R245 identified that the paid carer had cancelled and rearranged the appointment.

One carer reported "Nurse rang 9.30am with appointment for 4pm!!! This was just out of the blue and we were already out on activities all day." (R251), short notice appointments may be of benefit however given the 'punctuation' expressed it would be reasonable to believe that this carer did not appreciate the short notice.

R97 provided an indirect response to the question. They did not comment on inability to attend a scheduled appointment rather provided commentary on the requirement for the person to arrange their own appointment, "*the letter invited my son to make an appointment from the outset, they didn't set the appointment date or time, they invited us to.*" This approach by the service may prove problematic if the person is unable to make their own appointments.

**11.7 Q13. If you got a reminder from the GP just before the appointment was it:  
Other, please specify comment**

**22 respondents**

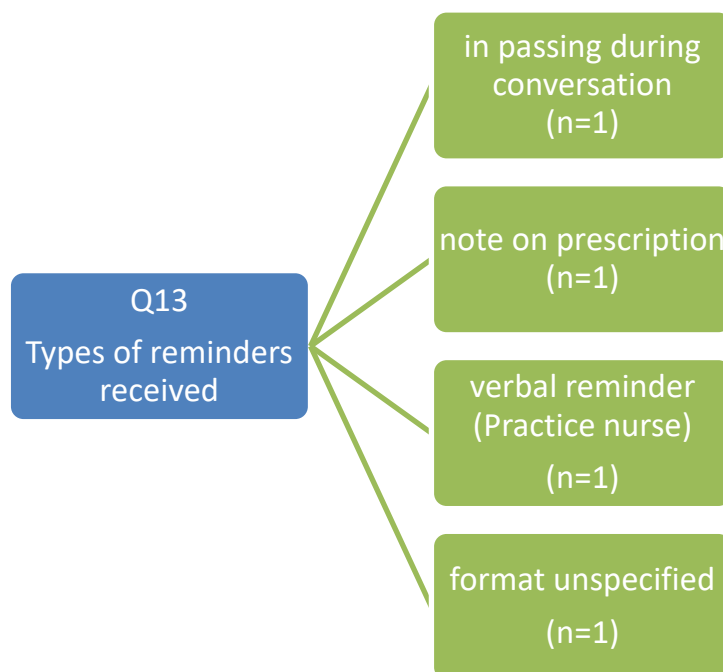
Reminder = 4

Opportunistic = 1

Null = 5

Not applicable = 5

Not invited = 7



*Annex Figure e: 11.7, Q13. If you got a reminder from the GP just before the appointment was it: Other, please specify comment*

Of those who received a reminder one, R1, was reminded during “*conversation*” with an unspecified person and R154 was reminded through a note on the prescription. R188 stated that “*The practice nurse told me verbally when I was seeing her myself.*”

R67 received a reminder (format unspecified) while R199 said “Only had one appointment October 2013. Not had reminder this year yet, so no doubt will have to phone myself to get daughter appointment.”

R259 self-reported that they “*they did the health check while I was there for something else.*”

**11.8 Q14. If the answer to Q10 is "No" why doesn't the person you care for attend an annual health check? Other, please specify comment**

**29 Respondents**

Individual influences = 9

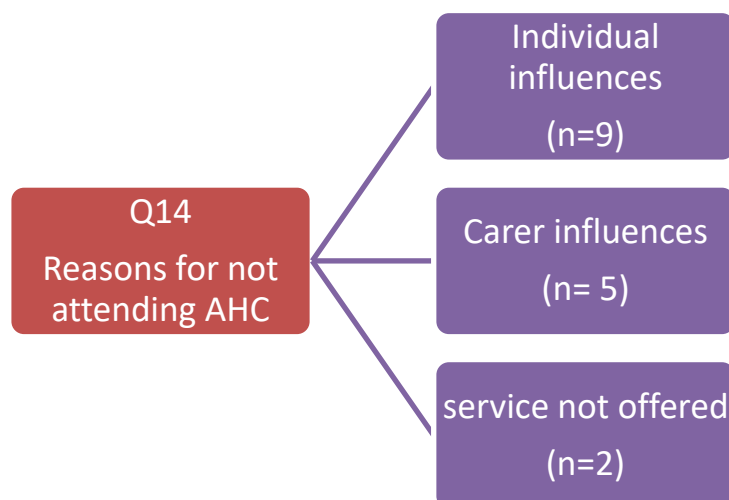
Carer influences =5

AHC not offered at health centre = 2

Null responses = 8

Not applicable = 4

Not invited to attend annual health check = 1 (responses relate to Q10)



*Annex Figure f: 11.8, Q14. If the answer to Q10 is "No" why doesn't the person you care for attend an annual health check? Other, please specify comment*

Responses ranged from factors encountered by the individual through to internal and external influences on the carer.

**Individual influences:**

Non-attendance due to the individual being unable to tolerate the interaction during the annual health check: examples include *"cannot tolerate the health centre/strangers touching him"* R166; *"has challenging behaviour and needs to be ill before going to doctors as that what he understands doctors are for"* R18.

For some, the focus on attending the doctor is for an intervention when one is unwell. This shift to preventative health care appears difficult for some with R202 indicating *"Issue in understanding going to the doctors if not unwell"*. R183 implies there is a change in situation

occurring *"She goes but it is becoming more difficult to get her to any medical appointments"*. The exact nature is unspecified and this may be a change for the carer or a change for the individual.

R188 identifies a tension in attending the GP appointments *"My son doesn't like going to the doctor, but will if I tell him he must for his own sake"*.

Some individuals benefit from opportunistic health checks during other routine appointments *"he sees the Doctor quite often with medical issues anyway."* R141); while another only undergoes prescription reviews (R113).

Alternative locations are sought where possible, *"less stressful/upsetting best done at home"* R106; *"Offered in school, but not through GP, did not take up in school as did not want to expose to unnecessary routine medical checks"* R40.

### **Carer influences:**

*"I am too physically disabled to take her. She won't talk to strangers and doesn't trust Dr's, and misinterprets a lot of what is said or asked of her (which makes her upset)." R 121.* R194 implied that the person does not attend due to their own availability *"No support for this other than me"*. Carer R84 expressed that it is *"too difficult"*.

One respondent (R99) identified a reliance on the paid carer and non-attendance due to staff non-acceptance of the appointment *"Their staff didn't accept the offer and we weren't aware they weren't taking him"*.

One responding carer appears particularly dissatisfied with their experience and is questioning the expertise of those providing the health check *"I would not take my mainstream children unless they were unwell, and feel the exposure to routine checks is not needed especially if there is no real level of expertise and understanding, if your young person has known the G.P. well then it may be a different story, we attend for medication review that takes 2 mins. Not sure routine health checks offer a lot otherwise unless by skilled team to cover all angles, benefits, wellbeing support"* R39.

### **AHC service not available:**

Two respondents (R19 and R265) indicate the annual health check is not offered at their surgery.

**11.9 Q15. If the answer is "Yes" to the person going for annual health checks please go to the next page of the survey. If the answer is "No" please add comments in the space below and go to the "comments page" at the end of the survey....**

### 53 respondents

Service not offered = 10

Not invited = 11

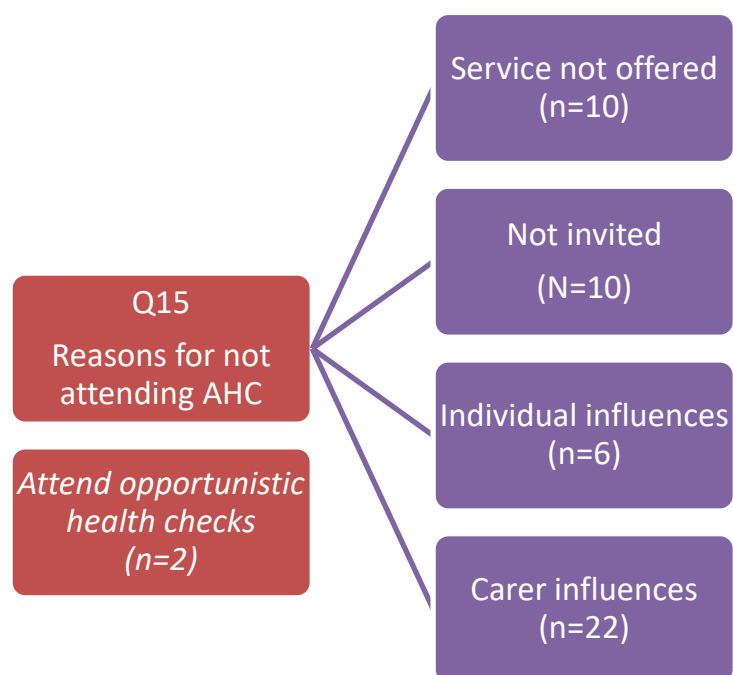
Individual influences = 6

Carer influences = 10

Lack of awareness = 14

Not applicable = 1

Null = 5



*Annex Figure g: 11.9, Q15. If the answer is "Yes" to the person going for annual health checks please go to the next page of the survey. If the answer is "No" please add comments in the space below and go to the "comments page" at the end of the survey....*

Respondents indicated that they have difficulty accessing GP appointments for a variety of reasons.

### Service not offered:

Respondent 19 approached their surgery to enquire about availability of health checks and were informed that it was not offered. A similar lack of service was encountered by R43, whilst R223 identified a lack of service provision for the person they care for stating that “*Young people with Asperger's<sup>1</sup> don't qualify for any care services in our authority*”. R124 stated “*I would take my son if it was available though he would need some preparation re: social stories*”; whereas R66 indicates “*Our surgery doesn't believe they have the funding to do these*”.

*“GP appts are very difficult therefore we avoid going unless there is a problem” (R84).*

One carer expressed uncertainty as to why the appointment was not offered making the assumption that opportunistic health checks are being undertaken so therefore did not require an annual health check (R86) “*Maybe didn't get annual health check as she already goes to doc office for various health issues.*” Further assumptions were identified by R186 indicating their GP didn't offer a health check because the person they care for “*does not like to have injections*”.

*“My daughter apart from her severe learning disability has many and complex health problems, we see consultants at hospital but not sure why we haven't come up on the GPs horizon.” (R226), whilst R113 states “Just have prescription reviews every year not had annual health check, but GP asked for blood test”* although the person's ongoing health is being reviewed it remains a concern for the carers that the individuals they care for are not receiving an annual health check.

### Not invited:

Carers indicated that the person had not been invited for a health check (R20, R65, R156, R187<sup>2</sup>, R240, and R250. R10 expressed frustration in that the annual health check is not offered and they also have difficulties attaining an annual face to face asthma review, “*it's being done over the phone with me!!!*” R231 received information about the annual health checks for the first time from their sons GP and confirmation that his name would be included in future invitation requests “*We've heard nothing yet*”.

R126 indicated they had never received an appointment; they arrange the appointment themselves. R77 also indicated a requirement by the carer to follow up referrals; they expressed their frustration “*Don't feel things are followed through. Got standard reminder for medicine review for my son (medication is part provided by GP part by Psychiatrist), when tried to make appt couldn't get one for over 3 weeks!! Don't feel I am supported as a Carer*”, “*The onus is placed on the Carer for this and to organise it for the adult with a disability. Follow up does not happen*” (R77).

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<sup>1</sup> (Asperger's is included in the study report as the carer reports the young person has a learning disability.)

<sup>2</sup> (Autism is included in the study report as the carer reports the person has a learning disability.)

### Individual influences:

There were several responses where the reason for non-attendance at an AHC was indicated as due to presenting difficulties such as *“autism, challenging behaviour resulting in physical violence when in a clinical setting.”* (R242), *“severe learning difficulties, Severe Autism and behavioural and communication difficulties, refuses to cooperate with health checks.”* (R220), *“Can't cooperate with it due to low mental capacity, SLD, autism and severe and challenging behaviour.”* (R2). Respondent 18 recounts a particularly difficult experience which influences future decisions regarding attending AHC *“last time I took my son for a check-up when he was well after a few mins he decided he wanted to leave and I made the mistake of putting myself in the way to prevent him from leaving. The challenging behaviour kicked in and I was slapped, kicked and had my hair violently pulled had to end up pinning him up against the wall till he calmed down and stopped lashing out but as soon as I released him he was out of the door and I had to follow to make sure he and others remained safe”*.

The priority here is for services to provide person centred support so these carers and others in similar situations feel supported to attend and that environments are safe.

### Transition:

Bureaucracy at time of transition was a key concern from one carer (R137) *“I think my son is stuck in NHS/SOCIAL services bureaucracy at transition so any triggers for an annual health check do not function for him”*.

Change in eligibility, identified by one carer, R111 stated *“I was told that because my daughter was entered for 2 GCSE's (Art and ICT which she didn't pass) she was no longer considered to be under the learning disability team, so I'm not sure how she is characterised by GP's”*.

### Carer involvement:

A further theme in this question was the impact upon attendance from the supporting person. R103 explained in their role caring for both a dependent child and a dependent partner attendance at the AHC is *“yes and no”*; R188 explains how a previous ‘experience’ has influenced their son’s attendance at AHC, *“If it wasn't for my wife and myself insisting he goes he would not go”*.

Eligibility for the AHC is based on the individual presenting with having an intellectual disability. R58 faces a personal challenge, stating *“that I do not want to tell the doctor in front of my daughter that she has got learning difficulties as I think it would be bad for her self-esteem, and that is poor enough as it is.”*

Proximity to the person is another significant challenge as main carer, living 200 miles away R194 recalls a detailed personal story expressing their sons (and son’s wife’s) vulnerability and complex health needs. The carers support is supported through a *“Solicitor..... and an objective assertive care manager”*.



Awareness of one's own health is also critical, *"when he is ill I have to accompany him to all appts ...It has to get bad before my son will advise that he feels un well"* (R156).

R155 appear unconcerned that the person they care for has not been invited for AHC, indicating *"... is not on any medication and health is good for a person of 24"* while R58 indicates their daughter is *"generally pretty healthy and hasn't seen a doctor for years"*, however they express concern about the time to make appointments *"To get an appointment takes around two weeks"* and express concern that staff are not aware of the person needs before the visit *"If she did have to go down I doubt that they would even realise she had moderate learning difficulties and was on the autistic spectrum unless I told them when I went with her as they never read anyone's notes very thoroughly when you do visit"* (R58).

One respondent (R99) identified their dissatisfaction with the service provided citing examples where paid care staff had not acted on the invitation for the AHC *"care home staff ignored 3 invitation letters my brother was removed from the gp register"* inferring that this had fatal consequences for their brother. Further implications are that the statistics for the surgery would show their percentage of completed annual health checks, rather than for those removed due to non-attendance, regardless of why this occurred, *"the gp surgery stats looked better"* (R99).

R166 states *"totally inaccessible to him"*, unfortunately they do not elaborate on their response so it is not possible to determine the meaning behind the response.

#### **Lack of awareness:**

Fourteen carers (R16, 47, 106, 109, 125, 137, 147, 156, 198, 207, 234, 241, 254, and 273) indicated a lack of awareness regarding the AHC. R16 expresses incredulity *"I cannot believe I've never been informed that my son should have annual health checks"*

Two parents, whose children are in transition to adulthood had not been informed of the AHC as part of this transition point in life (R137 and 207). With this recent awareness (R207) indicates they will be contacting the GP to arrange the AHC for her daughter *"She has severe Id and is non-verbal. When she is ill or in pain she self-harms as she cannot tell us so hopefully annual checks will help keep her healthy and happy"*.

R106 is aware of the AHC, but unaware that they should be initiated by the GP, they have secured health checks through *"... myself contacting learning disability health team and now a LD nurse is involved with by son's health checks"*.

For those who indicated recent awareness, one became aware through the GP (R231) while two became aware through social media (R47 and R207).

#### **Opportunistic health checks:**

Although the survey asked about reasons for not attending annual health checks two respondents recounted situations where the health check occurred but was not specified as an 'AHC'.

Respondents (R52 and R224) recounted positive experiences indicating that their GP is approachable and will provide any check on request and initiates referrals to other services as required. It is relevant to note that the contact with the GP is initiated by the carer rather than the GP.

#### 11.10Q16. Did a doctor or nurse do the AHC? Other, please specify comment

##### 42 respondents

Both GP and Nurse = 18

Health care assistant = 1

Awaiting = 1

Unspecified = 2

Didn't have an AHC = 20



Annex Figure h: 11.10, Q16. Did a doctor or nurse do the AHC? Other, please specify comment

No open comments given

**11.11 Q17. Are you happy with the way the person you care for was treated at the annual health check? Other, please specify comment**

**42 respondents**

Yes = 3

Uncertain/neutral = 3

Dissatisfied = 7

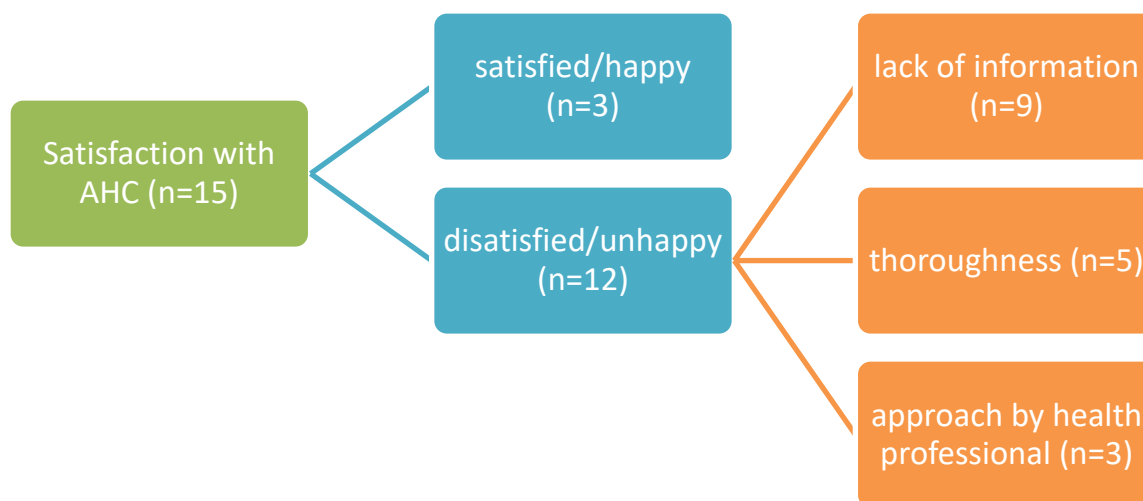
Lack of information = 2

Approach by health professional = 5

Null = 2

Not Applicable = 5

Didn't have an AHC = 18



*Annex Figure i: 11.11, Q17. Are you happy with the way the person you care for was treated at the annual health check? Other, please specify comment*

There were 42 respondents to this question however only fifteen indicated experience of the AHC upon which they could report satisfaction.

R112 expressed that they were happy with the way the person you care for was treated at the annual health check, no further detail provided.

While R183 indicated, they were happy with the limitation *“yes, but it is not in depth enough, not enough comms between professionals”* and R41 expressed satisfaction with the AHC but expressed *“it wasn't really a health check”*, unfortunately there is no further detail provided to indicate the type of check undertaken.

Several other respondents identified dissatisfaction with the experience, a combination of the following; check not considered thorough enough R80, R139 and R244, *“more checks .... are needed my opinion it was very basic”*, R193; *“It was done by one doctor without my knowledge and from what I could gather was very superficial”* (R218).

Lack of information about the health check led to dissatisfaction for R188 who stated *“I think as a carer I should receive some guidelines as to what to expect”*; similarly, for R199 *“Not sure what was meant to happen, so have no gauge of what “should” be done”*.

Approach by the health professional was cause for comment with R232 expressing that the AHC *“seemed to be a bother for the nurse”*; while R251 expressed that there was *“not much empathy with learning disabled person”* during the health check.

A positive experience was expressed by R178 who indicated the person was *‘treated well’* but stated from their perspective the quality of the check was better with the ‘previous doctor’.

Of particular note, R257 and R258 stated *“we are getting to scared to even go to the Dr for basic care”*. For health checks to be effective services must ensure that people are fully informed so they can make an informed decision to attend the check, but most importantly people must not be fearful and feel safe and confident in the service offered.

Of the remaining eighteen respondents identified the person they supported didn't have an AHC didn't have an AHC (R14, R59, R77, R81, R86, R89, R121, R124, R137, R167, R187, R192, R194, R198, R220, R231, R232, R236), however it is uncertain from the responses to this question (Q17) whether this means the individual was invited but not attended or was not invited to attend an AHC. R59 explained *“unable to do the health check because of his activity level”* however they do not indicate level of satisfaction regarding this experience while R89 explained the AHC did not occur as *“He does not like needles”*.

From these encounters, it is evident that care expectations are a factor in the level of satisfaction experienced, the need for detailed information about the components of the AHC is clear and would alleviate potential anxieties prior to and during the AHC. It would also provide carers with greater clarity in what to request where they feel the checks fall short. This information would also be of benefit in assisting to prepare the person who is attending for the AHC so they know what checks and test will be part of the AHC and aid the identification of opportunities for desensitisation.

A further aspect for attention is the interpersonal dynamics of the individual professionals delivering the AHC this is essential for effective communication and participation by all concerned.

**11.12Q21. Lifestyle advice (e.g. regarding diet, exercise, smoking cessation etc.)?  
Other, please specify comment**

**22 respondents**

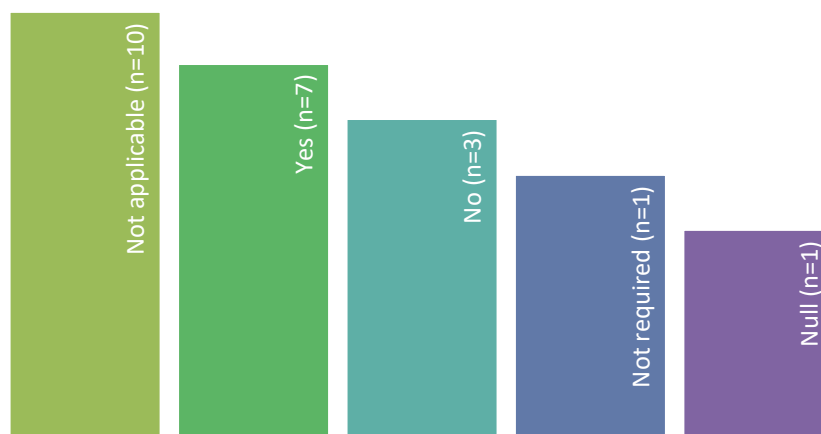
Not applicable = 10

Yes = 7

Null = 1

No = 3

Not required = 1



Annex Figure j: 11.12, Q21. Lifestyle advice (e.g. regarding diet, exercise, smoking cessation etc.)? Other, please specify comment

R41 explained that one role of the support worker is to provide a healthy lifestyle for the person.

R133 indicated that information was provided and that she is spoken to as the carer whilst R166 identified that lifestyle advice was not given as the person “*would not have understood*” no mention of whether this information was provided to a carer or in an accessible format.

A multi-professional approach was identified by R176 “*There is a consultant psychiatrist involved who advises on healthy diet. There also used to be a dietician involved*”, similarly R117 identified that “*The GP knows this service very well and we have regular contact with the practise. The GP had his notes and the history of service user with them and asked about diet etc., knowing that the staff at the service have experience and knowledge in healthy eating etc.*” This is a positive example demonstrating how the experience is positive for all concerned when the professions work together with the person and care provider.

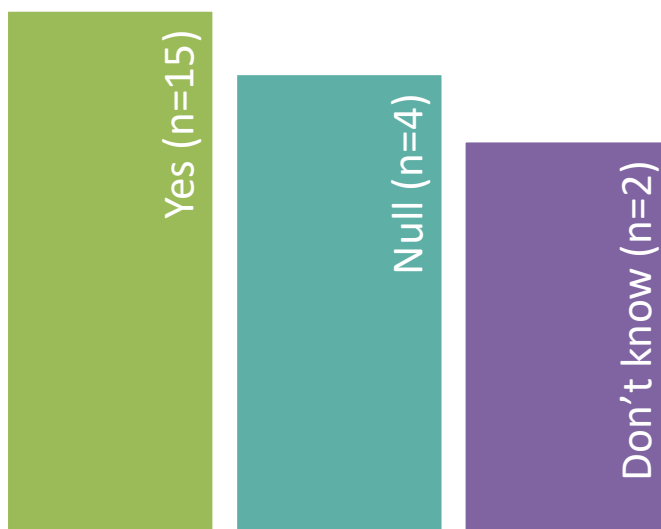
### 11.13Q25. Was the person given a Health Action Plan...comment

#### 21 respondents

Yes = 15

Don't know = 2

Null = 4



Annex Figure k: 11.13, Q25. Was the person given a Health Action Plan...comment

Of those who indicated they have a 'Health Action Plan (HAP)' R7 was given a copy to complete before the AHC appointment.

The remaining respondents identified that they have their own rather than one initiated and issued by the GP.

R117 and R263 indicate they have their own (service) version which the GP completes during the AHC appointment. R223 and R280 identified that the family and/or support team have developed their own HAP for the person.

R132 appeared dissatisfied regarding the use of the person's HAP stating 'Has a [HAP] from his placement - not mentioned at the [AHC] review'.

R250 indicated that the HAP was "*completed by Community Learning Disabilities Team*" and R131 identified that the HAP had been completed by the "*health facilitation team*"; however, they were uncertain whether the plan have been updated. Although it is positive to have a HAP it is important, for the person's health, safety and wellbeing that it is kept up to date.

R205 indicated that they were informed the HAP would be “*sent in the post*”, although this indicated the person will have a plan it is not ideal to send personal and sensitive information by post and the delay in receiving will result in a delay in the HAP being implemented.

For some who are aware of HAP’s, the availability is limited, R151 stated the HAP is “*not available to my son and wife.*” While R270 stated that they “*asked for the plan and was told they don’t have them*” this led to their making a complaint and is now under investigation by the Partnership Board for adults with LD.

#### 11.14Q26. HAP syndrome specific? Comment

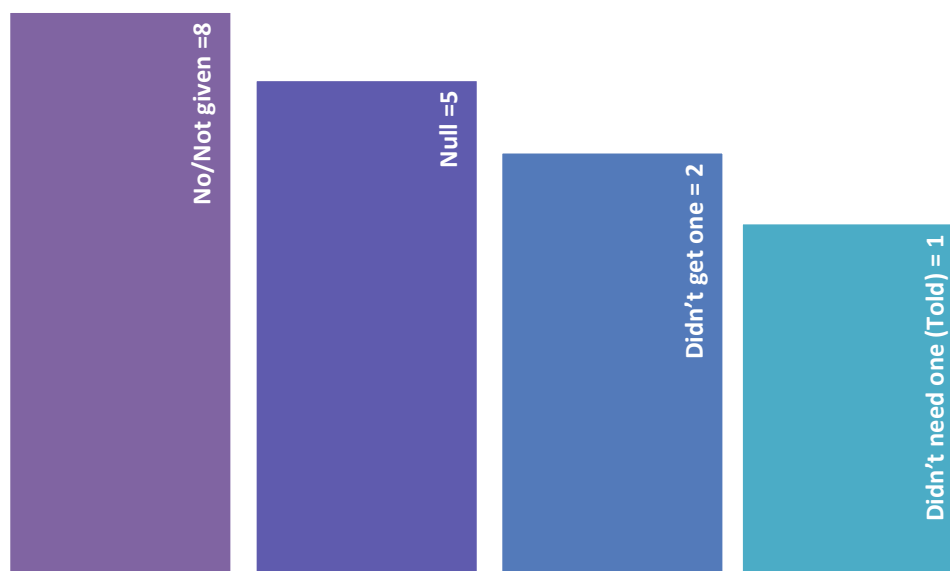
##### 16 respondents

No/Not given =8

Null =5

Didn’t get one = 2

Didn’t need one (Told) = 1



Annex Figure I: 11.14, Q26. HAP syndrome specific? Comment

No further syndromes were identified by respondents.

